UNITED FOR COMMUNICATION CHOICE

July 28, 2018

American Speech-Language-Hearing Association
2200 Research Boulevard
Rockville, MD 20850-3289

To the ASHA Board of Directors,

United for Communication Choice, a grassroots effort of individuals with disabilities, their families, and allies, was recently made aware that you likely will not be provided with complete and balanced views regarding the proposed position statements on facilitated communication and the Rapid Prompting Method that will soon come before you for deliberation. Specifically, we were alarmed to learn that letters opposing the proposals would not be shared with decision-makers.

More than 150 individuals submitted statements to ASHA strongly objecting to the proposals. These letters were written by longtime ASHA members, speech-language pathologists, occupational therapists, special educators, neuroscientists, psychologists, physicians, professors, judges, lawyers, grandparents, siblings, and—most importantly—users themselves.

The fact remains that no one on the Ad Hoc Committee that prepared the proposals has any direct experience as either a user or professional provider of these augmentative and alternative communication (AAC) teaching methodologies, both of which teach users AAC in the form of independent typing on a keyboard or iPad. Moreover, the Ad Hoc Committee refused to include or consult with anyone with such experience during the 10 months the proposals were being written. As such, we believe it is incumbent upon the ASHA Board to become fully aware of the extent of opposition to these proposals among people with disabilities themselves. To that end, we are providing you with the attached compilation of the 150+ individual letters to ASHA that were shared with us.

By refusing to share with decision-makers the perspectives of individuals with disabilities, their family members and allies, the Ad Hoc Committee is doubling down on its dangerous efforts to silence non-speakers. Just by issuing *proposed* statements, the Committee has achieved its apparent goal of directing public school systems throughout the United States to remove effective communication auxiliary aids and services guaranteed under Title II of the Americans with Disabilities Act. The Committee's actions have already contravened ASHA's own motto of "Making effective communication, a human right, accessible and achievable for all."

The attached letters complement the July 16, 2018 letter sent by a national coalition of civil rights and disability advocacy organizations. Since that letter was transmitted, several additional prominent national disability and civil rights organizations have reached out to support our efforts.

People without communication-related disabilities should not dictate how people with disabilities can communicate. To learn more about these two AAC teaching methodologies and see the difference they have made in the lives of thousands of nonspeaking people, please visit https://unitedforcommunicationchoice.org. There, you'll find peer-reviewed research that helps to explain why some people benefit from these AAC teaching methodologies, videos of advanced learners, and additional explanation of why the civil rights and disability community believes the proposed statements are factually incorrect, misguided, ableist, and dangerous.

We thank you in advance for your review and consideration of the important correspondence attached.

Sincerely,

United for Communication Choice

ATTACHMENT

COMPILATION OF LETTERS SENT TO ASHA

Disclaimer: The attached cover letter is the original version sent to ASHA on July 28, 2018. Letters that follow are a portion of the over 150 letters sent to ASHA from those who have granted permission to have their letters published.

June 11, 2018

Jessica Aysseh
Fairfield, CT 06824

To Whom it May Concern,

I am the parent of a non-speaking 13 year old child. I have also been a public school teacher in Westport, CT for 23 years. My daughter, Coco, was adopted from China at the age of 22 months. She has received early intervention and a myriad of therapeutic services from the first week she arrived in the United States. These interventions have included speech therapy, occupational therapy, physical therapy, social skills therapy, and EIBI as well as home ABA services under the supervision of multiple BCBAs. In addition to these traditional services, we have tried hippotherapy, music therapy, animal therapy, and aquatic therapy. She has received multiple services from our public school system since she was three years old. For the first three years, while she was in the public preschool, she made steady gains in speech production. From the time she entered kindergarten, all work on vocalizations ceased in favor of a focus on AAC and her speech production rapidly declined to her current lexicon of just a few words that she repeats compulsively with no deliberate intent. For the most part, her AAC training was focused on PECS training. After multiple hours a week of services, from the years 2008 until 2015, Coco mastered the ability - only when prompted - to add a noun to the end of the “I want” sentence, pull off the sentence strip, and request one of the 4 or 5 items chosen by her SLP on the “I want” page. Until the age of 10, this was the extent of her communicative abilities. At that time (age 10) her school SLP moved on to the “PODD” app. They prompt her to touch a therapist-chosen button, and report that Coco is able to request one of the 9 items on the page, when prompted. Most of the experts working with her believe she has limited language and cognitive ability. They are unable and unwilling to explore the role that apraxia plays in limiting her ability to motor plan and make deliberate movements to demonstrate her intelligence.

In July, 2015, I decided to give Rapid Prompting Method (RPM) a try. I was intrigued by its premise of presuming competence. I believe all people can learn. I believe, and always did believe, that my daughter deserved more than the segregated preschool-type lessons and mind-numbingly repetitive DTT she was receiving in her specialized EIBI school. I believed that she was entitled to real academic education. As a regular education teacher, I know good teaching when I see it. RPM is good teaching. In an RPM lesson, there are 4 goals: cognitive, tolerance, skill, and communication. The learner is presented with interesting content and there is back and forth between the teacher and the learner in a “teach-ask” format. RPM is not a method of communication. It is a teaching methodology that enables students to acquire communication skills through choice-making and eventually spelling. For ASHA to dismiss RPM as a communication method is misguided and unfair. It is a teaching style. Not a therapeutic intervention or a method of communication, but a teaching style.

Through RPM my daughter was able to hone her ability to choose her desired answer by pointing. With much work and practice, she was able to eventually apply this motor improvement to the skill of pointing to letters on a letter board. She is now able to spell and communicate her thoughts, wants, needs, creativity, emotions, etc. by spelling on a letterboard or keyboard. RPM is not her communication method. RPM is the method of academic instruction I use with her. Her communication method is spelling by pointing. If Coco was no longer allowed to spell out her thoughts on her letter board, she would be forced back into her old prison of silence and segregation. Being able to spell on a letter board has opened the world to her. She plans to attend college. She writes poetry. She is developing relationships - finally - with friends and family for the first time, at age 13.

Coco has been evaluated by 3 highly regarded SLPs. All 3 hold MA CCC SLP credentials. All are members of ASHA. All 3 were skeptical that RPM teaching could lead to independent communication. All 3 communicated with Coco and documented in writing not only that Coco is spelling completely independent of influence, but clearly possesses language skills that exceed her chronological age. If ASHA had already condemned RPM as a teaching methodology, these specialists would likely never have given Coco a chance to even communicate with them. All 3 recommend that Coco's school allow her to continue her current means of communication - spelling with the aid of a communication partner and continuing the goal of independent typing. This is a goal I have no doubt she will reach.

Coco's method of communication - spelling on letter board - is NOT facilitated communication (FC). No one is touching Coco as she spells. ASHA repeatedly tried to link RPM to FC. I have no interest in discussing the pros and cons of facilitated communication. But I do know that FC has no place in RPM or the way my daughter spells to communicate. Coco's movement on the board is not impeded or interfered with in any way. She receives minimal prompts. The communication itself - the letters she chooses - is not prompted in any way. She is prompted to initiate movement, as her apraxia sometimes makes this initiation difficult. She gets "stuck" or "frozen." In her sessions at school with her SLP she is constantly prompted - verbally and physically - in her communicative efforts. There is far more prompting and prompt-dependence than I would ever engage in with an RPM session or when Coco is openly spelling out her thoughts.

I am extremely concerned that the Ad Hoc committee who released the recent statement on RPM has refused to consider input or evidence from users and ASHA members with experience in these methodologies. I would welcome any of these committee members into my home to see my daughter communicating. I cannot imagine anyone interacting with my daughter in person would want to then deny her the ability to spell her thoughts. I cannot imagine anyone wanting to sentence her to a life of touching teacher-chosen buttons on an app that only addresses her basic needs after they witnessed her describing her thoughts, desires, fears, and poetic voice. Please - anyone from ASHA - come meet her.

Policy decisions of such magnitude should involve a careful and unbiased examination of viewpoints. Instead, ASHA'a Ad Hoc Committee is comprised of individuals with histories of personally attacking and making disparaging remarks about RPM methodology and even individuals who use this methodology.

The proof is in the pudding, so to speak. The evidence is alive and well in my home in Fairfield, CT. I invite you to come meet and communicate with the evidence.

Best regards,

Jessica Aysseh
jessicaaysseh@gmail.com

June 26, 2018

Barry Prizant

bprizant@gmail.com

To the ASHA committee on the Position statement on FC

As an SLP with more than 40 years experience with persons with a full range of communicative challenges, including many on the autism spectrum, I am writing to express my concerns about what I consider to be an extreme position taken by the ASHA position statement on FC and communicative modes that involve spelling with support. I am not directing my comments specifically to the statement on RPM, because I have no experience with observing this method in practice. (I have received correspondence over the past few years from parents I have known who have indicated that RPM was very helpful for their son or daughter). I do have much experience with individuals who receive support in spelling or accessing displays on high or low tech communicative displays or devices. I also have much experience in general as a clinician and researcher with individuals on the autism spectrum, which has always served to question and reshape my concept of autism, how we define intentional communication, and the unfortunate consequences of having strong and inflexible biases about the "truth" regarding the behavior and experiences of people on the autism spectrum. Much of this work has been published in peer-reviewed publications in speech-language pathology, child psychiatry and psychology and neurology, on topics ranging from echolalia, assessment of communicative intent and family-centered intervention.

As I received the invitation to submit comments from Elizabeth Haines on June 19 and have been traveling for work in Europe and Germany since June 7, I must honestly say that these comments have been hastily composed during my flight back to the US on June 25, the deadline for submission of comments.

Mu concerns include the following:

1. The definition of FC seems sufficiently unclear to allow this position statement to be applied to related communicative options that do not necessarily involve direct physical support to a target. Also, the definition refers to "physical support" but does not address circumstances in which physical support is used in initial stages and then is no longer used if an individual acquires greater control in motor movements. I have observed clinicians provide support for visual attention to a letter board or communicative display, but who are not directing the person's point or touch to a specific target – does this fall

under the definition of FC according to this statement? This became most clear to me during a two day visit in February, 2018 to the University of Virginia when I spent some time over two days with 9 non- or minimally speaking adults with autism. During my time with them, I sat in close proximity to them, side by side, or observing from behind, as they answered questions I posed to them as we sat together in a group. Some responded immediately to my questions with no or minimal support for attention to the board, with on-topic and at times, surprisingly insightful responses. They all scanned the boards or keyboard on an alphasmart – not looking in opposite directions away from their letterboards as famously depicted in Doug Biklen's early FC tapes. At times, they commented on (agreed or disagreed) with others in the group. One or two required more persistent support for attention to the letter board, but in no, and I mean NO instances where they physically or gesturally directed to specific letter targets. Additionally, each often shifted gaze to me as they formulated responses or as they concluded their spelled message, a clear behavioral indicator of communicative intent. I am aware of some claiming that the facilitator in such instances may be providing subtle cues, even unconsciously, but I did not observe any of that and, of course, such claims are inconsistent with all we know about autistic person's abilities limited ability to read nonverbal signals. Each person I observed and interacted with remained well-regulated emotionally and focused on the exchange. As I understand it, most had years of intervention with speech and other AAC options, with minimal success. I was informed that most had required some degree of physical support/resistance in initial stages of training that probably would meet the definition of FC for some, but all were now mostly independent, and certainly appeared motivated to express their intentions. Many spoke about problems in controlling their bodies.

To be honest, I was skeptical prior to having these meetings at the University of Virginia, but had no doubt that these individuals authored the messages during these meetings over my two day visit. Members of the ASHA committee may be inclined to dismiss this experience as "anecdotal", but those of us raised in the social-pragmatic movement would likely consider such an experience at least as, if not more "authentic" than clinical trials "testing" the authenticity of communication, especially for individuals with significant social-communicative challenges. Furthermore, in my consulting and clinical practice, I have met other individuals with autism who now type independently but reportedly began with varying degrees of physical support. I also have observed some individuals with similar histories present at conferences, including some who speak but indicate that their communicative ability is greatly enhanced when they can formulate what they wish to say first by spelling. A related observation I have observed with many individuals is unexpected literacy skills, which in the most striking forms is known as hyperlexia, and is clearly documented in the autism research literature.

Additionally, as a clinician who has extensive training in being family-centered in my practice, I met with most of the parents during this visit to the University of Virginia who shared how life-changing their adult children's ability to spell to communicate has been. These were not desperate parents "new to it all" looking for miracle interventions, these were educated and informed parents who had been through years of promises about the effectiveness of interventions, including some that are claimed to be the most effective such as ABA, but who now have expressed how the quality of life for their adult children and the family has been enhanced greatly. Most also shared how their children's emotional regulation has greatly improved with a significant reduction in problematic behavior as their ability to communicate has improved, a comment made by a few of the adults in response to my questions. Family-centered practice requires that we listen to, collaborate and build trust with parents and family members. Is ASHA suggesting we follow an "expert" model and simply tell parents such as these that they are wrong in their beliefs and assumptions based on some studies with individuals who may bear no or little resemblance to their own children? We certainly should discuss the controversies surrounding any intervention approach when parents are made promises about treatment outcomes, which by the way, should also include "established" interventions such as ABA, but I have grave concerns about shutting down any options unless the potential degree of harm significantly outweighs the potential benefit. On this point, I obviously disagree with the committee's opinion.

2. I also have great concerns about the implied and certainly inaccurate use of the concept of evidence-based practice in this statement. As I have published a short article on this topic in 2011, I have excerpted some relevant sections and have attached the full article. In my opinion. the FC position statement is inconsistent with the definition and spirit of EBP – that only peer-reviewed research should be the source of evidence to support our practices.

"Evidence-Based Practice Defined"

Evidence-Based practice is a concept initially introduced by and borrowed from medical practice. Over the past decade, it has been adopted by the behavioral sciences (e.g., psychology, communication disorders, occupational and physical therapy) and educational fields.

Let's consider how EBP has been defined. According to the American Psychological Association (APA, 2005), the "definition of EBPP [evidence-based practice in psychology] closely parallels the definition of evidence-based practice adopted by the Institute of Medicine (2001, p. 147): 'Evidence- based practice is the integration of best research evidence with clinical expertise and patient values.' The APA goes on to assert that "Evidence-based practice in psychology (EBPP) is the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences" (APA, 2005). I have italicized portions of the previous definitions to underscore that decision-making in EBP is not strictly confined to the issue of research evidence, but also takes into account the expertise of the clinician and family / patient preferences and values.

The American Speech-Language-Hearing Association (ASHA) further emphasizes these points by noting that,

"In making clinical practice evidence-based, audiologists and speech-language pathologists—recognize the needs, abilities, values, preferences, and interests of individuals and families to whom they provide clinical services, and integrate those factors along with best current research evidence and their clinical expertise in making clinical decisions"(ASHA, Evidence-Based Practice in Communication Disorders, 2005).

To summarize, currently accepted definitions of EBP indicate that research should be used, when available, as an important source of evidence to guide clinical and educational decision- making, but other factors must be considered as well. These factors include: clinical expertise based on experience (referred to by some as 'wisdom-based practice'); educational and clinical data about effectiveness of practices; family preferences; individual differences in children and families; and when appropriate, feedback from the client as to the effectiveness of the practices. Elevating research findings to a position of predominance or supremacy over these other factors, or to the exclusion of these factors - though commonly the case—constitutes a misuse of EBP. In my experience, the majority of practitioners, and many parents, construe EBP as meaning research-based ONLY, a position that continues to be perpetuated by many professionals and agencies serving persons with ASD. Given the current tenuous and preliminary state of treatment research in ASD, many of these "other" factors (professional expertise, family preferences, individual differences, etc.) should play a significant role in such decision-making."

In this article, I then go on to describe the appropriate use of EBP (EBP-A) and inappropriate use of EBP (EBP-N) (see attachment). One criterion for inappropriate use is when the concept of EBP is applied primarily to restrict or condemn the use of a particular intervention, especially when significant controversy remains, and when there is evidence, even if qualitative and anecdotal, that the intervention may be of help for some individuals. I believe that a case can be made that evidence of significant facilitator influence may represent inappropriate practice in providing support for individuals in spelling to communicate. Many similar cases can be made for inappropriate practices in interventions such as Applied Behavior Analysis that have resulted in extreme prompt dependency, passivity and even increases in anxiety when aversive consequences have been used, yet based on such findings, no one is arguing that all ABA practices should be banned.

Other related concerns:

3. From my knowledge of the research, the number of negative instances of facilitator influence causing "harm" is greatly exaggerated as critical justification for "banning" the practice of FC or any approach that superficially resembles FC such as the use of spelling boards. I believe such instances are easily superceded by reports of parents, disabled individuals and professionals of the benefits of interventions that involve supports to communicate.
4. I am not aware of any objective support for the claim that use of FC or spelled communicative options have replaced other forms of AAC. In my experience, spelled communication options have been introduced after progress with other AAC options have not been successful, or is actually used as a complementary approach with other forms of AAC.
5. The focus of the statement is primarily on the specific treatment technique in question (FC) with virtually no comments on individual differences in developmental profiles of persons with ASD. For example, there is no discussion of the clear research evidence of learning and neurological profile differences across the spectrum of persons with ASD and other neurodevelopmental disorders, such as documented motor and movement disturbances, hyperlexia or motor speech disorders, that may help to explain why communication through spelling may possibly be a "real" phenomenon for some individuals but not necessarily for others. In other words, should the "door should be left

open" as we learn more about motor/movement disturbances, motor speech disorders and precocious self-taught literacy abilities (hyperlexia) in ASD and related disabilities? In other words, if we only focus on treatment "technique", and not on great variability of developmental profiles observed in persons with ASD and related disabilities, are we missing an essential factor in the equation?

6. I have concerns about the overuse of the terms "pseudoscience" or "junk science", which in my opinion, have become unhelpful clichés that most often are applied or have been applied to interventions (including our own SCERTS Model) that are clearly evidence-based but are in conflict with the biases or belief systems of those who use these terms . In my experience, those who have used such terms often 1) do not understand the intervention in question and/or 2) simply have a strong bias or in extreme cases, a personal vendetta or strong negative position against the approach in question. The notion that there are absolute truths and "cast-in-concrete" conclusions in the trajectory and development of social science is limiting and detrimental to the process of acquiring and applying knowledge, especially in reference to poorly understood conditions such as autism and persons who are greatly challenged in acquiring speech as a primary mode of communication.

One last comment:

Over the past two decades, I have participated in a number of meetings on the "State of Science in Autism" at NIH in which claims of respected and published researchers have since been overturned. These included statements that there was no evidence of

1) sensory processing issues in ASD (now one criterion for diagnosis as part of DSM 5 criteria)
2) motor planning or movement disturbance issues in ASD (now documented in multiple studies),
3) any interventions being effective or evidence-based except for ABA (a false claim still perpetuated by some).

Our understanding of persons with ASD and neurodevelopmental disorders in developing rapidly, and to shut down any practice or line of research, or to claim that we know enough is, in my opinion, premature. Certainly, we need to be aware of potential influences of all support partners, and the negative consequences of overly supporting any individual, but to prevent any potential options from being explored is of great concern for me from a human rights perspective. This same concern about limiting communication options was expressed again from a human rights perspective by researchers and autistic people at the 2017 United Nations World Autism Awareness Day, a conference in which I participated.

Barry M. Prizant, Ph.D., CCC-SLP
Adjunct Professor
Artists and Scientists as Partners
Brown University
ASHA Fellow (1995) and ASHA Honors recipient (2014)

June 21, 2018

Dennis R. Proffitt

drp@virginia.edu

DENNIS PROFFITT
DEPARTMENT OF PSYCHOLOGY
P.O. BOX 400400
CHARLOTTESVILLE, VA 22904

To: American Speech-Language-Hearing Association Attn: Board of Directors

From: Dennis Proffitt, Commonwealth Professor of Psychology and Director of Cognitive Science Degree Program, University of Virginia

Re: Position statements on Facilitated Communication (FC) and Rapid Prompting Method (RPM)

Dear ASHA Board:

I am writing to recommend that you not adopt the position statements on FC and RPM. I have closely observed a group of young autistic adults, the Tribe, from Northern Virginia who use a letter board to spell out words and sentences. Although this technique is neither FC nor RPM, it is a form of communication through spelling, and thus, may be viewed by some as falling within the scope of the position statement.

Two years ago, I attending a meeting of the Tribe with a UVA class instructed by Professor Jaswal. I observed members of the Tribe using the letter board technique to communicate. I came to the meeting skeptical about whether its use by autistic people was genuine or an instance of wishful thinking. My initial observations did little to reduce my doubts as some members of the Tribe seemed to stab at the board without communicative intent.

About an hour into the meeting, I attended a round-table discussion and sat next to a Tribe member. At one point, he expressed a desire to contribute and was presented with the letter board. He spelled out his sentences way too quickly to have been taking cues from the person holding the board, and more importantly, what he wrote was so apt, profound, and unanticipated that I cannot imagine that he could have been influenced by the person holding the board. I have absolutely no doubt that this young man was communicating fluently with the letter board. As the meeting progressed, I was repeatedly impressed with many, but not all, of the Tribe member’s ability to communicate with the letter board.

I am confident that at least some non-verbal autistic individuals are able to learn to communicate effectively using the letter board. I encourage you not to support the position statements as their approval may curtail the letter board’s use, and thereby, deprive many autistic individuals of a means to communicate.

Sincerely,

Dennis Proffitt

Cathie Davies

cathiedavies@optusnet.com.au

Do you agree with the proposed position that FC should not be used?

(Yes/No)
No

Position Comments

Lines 12-14: It is the position of the American Speech-Language-Hearing Association (ASHA) that facilitated communication is a discredited technique that should not be used.

- The position statement and the review on which it is based (Schlosser et al., 2014) are of inadequate quality to support this statement, as discussed below.

Line 15: *There is no scientific evidence of the validity of FC*

- It would be informative to know the committee's definition of "scientific evidence".

- The only empirical study of FC referenced by the committee is a review, Schlosser et al. (2014), which
  - Dismisses any experimental results suggestive of successful communication.
  - Fails to critically evaluate the quality and validity of experimental studies.
  - excludes all sources of evidence other than experimental message passing studies, including studies based on qualitative and mixed designs; clinical evidence (a vital component of Evidence Based Practice); and commentary (peer reviewed and otherwise) based on the lived experience of stakeholders.

- The ASHA draft Position Statement not only excludes discussion of non-experimental studies. The assertion that "there is no scientific evidence" denies the existence of such studies, implying that they have never been conducted.

- See "Systematic Review comments", below, for further comment.

Lines 15-18: … *there is extensive scientific evidence - produced over several decades and across several countries - that messages produced using FC reflect the voice of the "facilitator" and not of the person with a disability.*

- It is acknowledged that the response produced in experimental message passing studies may reflect the stimulus seen or heard by the facilitator, rather than that delivered to the person with a disability. However it goes beyond the data to interpret this as control by the facilitator. A plausible rival hypothesis is that, in an unfamiliar, clearly high-stakes activity, FC users may actively seek cues from their facilitator in an effort to get the "right" answer.

- Endlessly repeating the same experiment cannot eliminate rival hypotheses. A progressive research program is required. Schlosser et al. (2014) summarily excludes consideration of studies that may provide further insight into this question, while the ASHA Draft Position statement's assertion that there is "no scientific evidence" implies that such studies were never conducted.

The importance of alternative approaches to research is widely acknowledged. For example:

- a report by the American National Research Council (NRC), tasked with presenting the position of the research community on educational research, stated that: "If a research conjecture or hypothesis can withstand scrutiny by multiple methods its credibility is enhanced greatly" (NRC, 2002, p.64).
- Authors of the report were intent on dispelling "the myth that science is synonymous with a particular method" (Feuer, Towne, and Shavelson, 2002, p.31): "No method is good, bad, scientific, or unscientific in itself: Rather, it is the appropriate application of method to a particular problem that enables judgments about scientific quality" (Feuer, Towne, and Shavelson, 2002, p.32)
- In the same year, an advanced text on experimental and quasi-experimental research noted that: "observations can approach a more factlike status when they have been repeatedly made across different theoretical conceptions of a construct, across multiple kinds of measurements, and at multiple times" (Shadish et al., 2002, p. 16).
- Even Professor Shane, a member of the current ASHA FC committee, writing with a colleague, said: "Most experiments have some methodological flaws, but when consistent results are obtained in a number of experiments, each using somewhat different methods and flawed in different ways, the evidence has converged and strong conclusions are warranted" Green and Shane (1994, p.163). (It would appear, due to the exclusive reference to "experiments", that Professor Shane may consider "scientific" and "experimental" as synonyms. It should be clear from the other quotes in this section that they are not.

Line 18: *… there is extensive evidence of harms related to the use of FC.*

- While there is evidence of harm related to the use of FC, it is anecdotal evidence. As such, it is difficult to know the exact circumstances surrounding the event or events. Note that anecdotal evidence that may be interpreted as supportive of FC has been completely excluded from consideration by Schlosser et al. (2014), on which the ASHA draft position paper is based.
- FC "best practice" has been devised to minimize the risk of harm. In most of the situations reported, it appears likely that harm could have been minimized or avoided if "best practice" guidelines had been adhered to. Note that facilitator training and professional oversight of practice will be dismantled and the risk of harm increased if the ASHA draft position statement stops professionals from taking this role. This will significantly increase the risk of harm.
- There has been no systematic attempt to balance the risk of harm against the potential benefits of FC. FC proponents argue that, in general, risks can be managed and are

outweighed by benefits to the communicators, to their families and carers, to professionals who work with them, and to the systems and societies within which they live and work.

Lines 19-20: *Information obtained through the use of FC should not be considered as the voice of the person with a disability.*

- See discussion of specific "harms" under "comments about the FC definition", below.

Do you have any comments about the FC definition? If so, please provide below.

Definition

- Due to a paucity in research, the most salient information about FC currently remains in the hands of practitioners. Any effort at definition by habitual detractors, (a description amply applicable to at least four members of the ASHA ad hoc committee), risks misinformation at the most basic level, either through ignorance or through a deliberate attempt to set up a "straw man" for which support would appear nonsensical.

Line 24: "Facilitated Communication (FC), also called "Facilitated Communication Training" …

As defined in the first text book on the topic (Crossley, 1994), FC is appropriately described as "an assistive communication technique" (Crossley, 1994, pp131-132), while Facilitated Communication Training (FCT) is a teaching strategy that encompasses "best practice":

> Facilitated communication training is a teaching strategy in which a communication partner (facilitator) helps a communication aid user overcome neuromotor problems and develop functional movement patterns. The immediate aim is to allow the aid user to make choices and to communicate in a way that has been impossible previously. When the student's skills and confidence increase, the amount of facilitation is reduced. The ultimate goal for students it to be able to use the communication aids of their choice independently (Crossley, 1994, pp12-13).

The term FC is commonly used to refer to both FC and FCT, however the distinction is important and worth making.

Lines 25 to 28 describe FC as a technique "whereby individuals with disabilities and communication impairments allegedly select letters by typing on a keyboard while receiving physical support, emotional encouragement, and other communication supports from facilitators" (Schlosser et al., 2014, p. 359).

This first part of the definition proposed by the draft ASHA Position Statement is drawn from Schlosser et al. (2014). Please note that:

- Use of the term "allegedly" is immediately prejudicial.
- Schlosser et al. (2014) acknowledged that FC also includes the pointing to pictures or objects but excludes such communication from the definition because "the focus of this review is on typing" (Schlosser et al., 2014, p.359). This information is not reproduced in the ASHA draft report. The focus on typing appears to reflect concern over

> "unexpected literacy" exhibited by FC users. (See comments on hyperlexia under "Additional Feedback".

Lines 28 to 31: "The defining feature of FC is that a "facilitator" provides physical support in an attempt to help a person with little or no speech to point to pictures, objects, and printed letters and words on an alphabet board or keyboard".

- This second part of the definition appends a reference to pictures, objects and words to Schlosser's focus on typing. It is important to recognise that "communication" and "literacy" are two quite separate constructs. It is not clear whether the focus on literacy impacted the selection of studies for Schlosser et al. (2014). If it did, use of that review as the only empirical reference on FC cited by the ASHA draft Position Statement appears to be questionable at best.
- This second part of the definition emphasises physical support. Physical support has been the most controversial aspect of FC, however it is only one aspect of the dynamic, person-centred support that may be provided. The focus on physical support is prejudicial.

A more balanced definition was provided in ASHA's 1994 Technical Report:

> "Facilitated communication (FC) is a technique in which physical, communication, and emotional support is provided by a *facilitator* to an individual with a communication disorder (*communicator*). With assistance, the communicator points to symbols such as letters, pictures and/or objects" (ASHA, 1994, "Introduction", pagination not available).

As appropriate in respect of a strategy that is flexibly applied according to the needs of the client and the demands of specific contexts, this definition is augmented by practical descriptions of techniques based on "instructors' clinical experiences and hypotheses" (ASHA, 1994, "Facilitated Communication: The Technique", pagination not available).

It should be recognized that treatment integrity is less easy to assess in respect of FC than it is for some interventions. Implementation of the Picture Exchange Communication System (PECS), for example, is outlined in: "a detailed and comprehensive manual that precisely describes the teaching procedures for the six phases of the PECS protocol" (Travers, Tincani, Thompson & Simpson, 2016, p.94).

FC, on the other hand, is not a cookie-cutter intervention.

Respect for clinical judgement, based on experience, is a central tenet of Evidence Based Practice (EBP) models. For example, as noted in the context of Evidence-Based Medicine (EBM): "clinical expertise is the crucial element that separates evidence-based medicine from cookbook medicine and the mindless application of rules and guidelines" (Haynes, Sacket, Gray, Cook, & Guyatt, p197). Similarly, in the context of evidence-based practice in psychology (EBPP): "Research suggests that sensitivity and flexibility in the administration of therapeutic interventions produces better outcomes than rigid application of manuals or principles" (American Psychological Association Presidential Task Force on Evidence-Based Practice, 2006, p.278).

Under these circumstances, an emphasis on homogeneity in delivery of FC support would reduce both construct and external validity.

Appropriate training, clinical expertise, and ongoing support from a network of skilled and qualified practitioners is essential to disseminate and guide ‘best practice’ in both clinical and research contexts. Note that “best practice” has been shaped by over more than a quarter of a century, though local and international consultation and collaboration between practitioners.

Harms

Lines 34-35: In the years since [ASHA’s 1995] position statement, there has been no evidence of benefit

- It should be recognized that the only reason the ad hoc committee has found no evidence of benefit is because any such evidence has been deliberately excluded by Schlosser et al. (2014), the only empirical study of FC cited by this draft position statement.
- Discussion of evidence is misplaced in the definition. See discussion under “Systematic Review Comments”.

Line 35: and only growing evidence of the lack of efficacy

- “Growing evidence of the lack of efficacy” appears to refer to the endless repetition of message passing experiments, the validity of which has not been investigated. Excluded material referred to above provides ample reason to question the validity of message passing experiments.
- Discussion of evidence is misplaced in the definition. See discussion under “Systematic Review Comments”.

Line 36: and of its harms.

- Discussion of harm is misplaced in the definition.
- With regard to individual alleged harms, see comments below.

Lines 36-37: The risk is that FC may … lead to false allegations of sexual abuse and other harms …

Controversial and life changing communications

“Best Practice” includes protocols that may be followed to minimize harm in the event of high stakes communication. These protocols were briefly alluded to in the 1994 ASHA Technical Report: “Facilitators have been advised to attempt to confirm the allegation with a different, naive, experienced facilitator” (ASHA, 1994, Legal Implications, pagination unavailable).

It is important to recognise that the vast bulk of facilitated communications are neither controversial nor life-changing. Any suggestion that the challenge of dealing with disputes outweighs the benefits of improved communication must be examined very closely.

When individuals previously thought unable to participate in decision making are suddenly empowered to do so, it may be confusing for them and confronting for those around them. However, it is well known that, in the absence of other alternatives, an individual's dissatisfaction may be registered through "challenging behaviour". Access to more efficient communication is generally expected to reduce challenging behaviour and increase self-determination and quality of life.

It is recognised that some communications may be uncomfortable or difficult to deal with. There may be valid questions regarding meaning, accuracy, and - in the event of legal issues - rules of evidence. Such serious matters are certainly problematic, but they are not exclusive to FC.

FC "best practice" includes detailed protocol outlining how to respond to controversial or life-changing communication, based on over a quarter of a century of experience and practice in the field. Such protocol cannot resolve all issues that may arise, but it does provide a road-map that may be used to navigate these rare, but difficult situations.

Abuse Allegations

With regard to abuse allegations, the ASHA 1994 Technical Report made the following comments:

> Senn (1988) estimated the incidence of abuse experienced by people with developmental disabilities to be up to 32% in men and 80% in women. A recent report by a physician responsible for medical examinations following abuse allegations indicated that of 1,096 allegations she followed in a 2-year time span, 13 were made via facilitated communication. There was corroborating evidence for 11 of these allegations (of the 11, 7 were found to have medical evidence of abuse), suggesting that many of these children had been sexually abused (Botash et al., in press)" (ASHA, 1994, "Legal Implications", pagination unavailable).

There does not appear to be any research addressing the incidence of abuse among FC users, however evidence of higher rates of abuse in vulnerable populations does exist, for example:

- Sullivan and Knutson (2000) found that children with disabilities are 3.4 times more likely to be maltreated than nondisabled peers
- Kvam (2000) found that, although North American studies indicated that disabled children are at 2–3 times greater risk of being sexually abused than non-disabled children, caretakers do not seem to recognize the signs until they are quite obvious.
- Marge (2003) cites a range of clinical and research evidence highlighting the greater vulnerability of persons with disabilities to victimization when compared with individuals without disabilities.
- Bornman & Bryen (2013) found that the vocabulary needs of AAC users who are unable to spell their messages continue to be of concern in respect of sensitive topics such as crime and abuse.

Speech Pathology Australia (SPA) recognises the problem with the following comments:

> *People with little or no functional speech, and those with disabilities leading to their dependence on other people, are vulnerable to and at risk of abuse or exploitation (Bryen & Wickman, 2011)* (Speech Pathology Australia, 2012, p.21.)

Despite recognition of the vulnerability of this group, anxiety over the possibility of abuse allegations and the need to respond to them appears at times to outstrip concerns about their accuracy. Is it really being suggesting that people should not be given the means to communicate in case they say something controversial?

Prior to the review of FC in Queensland, Australia, the public sector had a well-developed protocol for dealing with controversial and life changing communications. Although the Queensland reviewers did not comment directly on this document, their conclusion regarding the Facilitated Communication Procedures (DSQ, 2005a) was that:

> … the procedure is written in such a way as to recognize and address a large number of the concerns raised about FC during the last 20 years or so … (Mazerole and Legosz, 2012, p.180).

Despite this, the conclusions of the Queensland review of FC were negative, and the status of related policy is now unclear. FC is still being used to support some Queenslanders, but without professional oversight risk is increased.

It should be recognised that it is extremely difficult for FC users to comply with the rigorous protocol for dealing with controversial and life changing communications, and that this may limit the number of allegations referred to authorities for investigation. However the protocol is not as limiting as withdrawal of communication support would be for individuals who have no effective means of access to complex communication other than FC. I refer the reader to research by Bornman & Bryen (2013), who found that the vocabulary needs of AAC users who are unable to spell their messages are generally not met in respect of sensitive topics such as crime and abuse.

Opportunity Cost of FC

Lines 37-43: it may also hinder or delay access to appropriate services and effective forms of intervention, including augmentative and alternative communication (AAC; see Allan, Schlosser, Brock, & Shane, 2017; Brady et al., 2016; Iacono, Trembath, & Erickson, 2016; Logan, Iacono, & Trembath, 2017; Romski & Sevcik, 2016; Snell et al., 2010; Walker & Snell, 2013), applied behavior analysis (ABA; Virues-Ortega, 2010; Vismara & Rogers, 2010), and other interventions with a sufficiently supportive evidence base (ASHA, n.d.-a).

- It is ironic that the draft Position Statement cites so many references relating to alternative interventions, and only one empirical study of FC (Schlosser et al., 2014).
- Facilitated Communication Training in no way precludes the use of other supports, programs, strategies, therapies, etc. in an individual’s program. Contact with a team of professionals is actively encouraged.
- Far from being exclusive, FC may enable individuals with complex communication needs to access many interventions and activities that would not otherwise be open to them, with benefits for joint attention, self-determination, and social interaction.

- FC is generally not offered to individuals whose communication needs can be met by other strategies. Nor does it preclude continued use of existing strategies. As SPA has advised:

> Providing multimodal communication means offering a range of communication systems and strategies as options to enable the person the greatest degree of choice in using a preferred modality in any given situation. … It is recognised within the AAC field that no one method or technique will fulfil every communication need in every situation (Beukelman & Mirenda, 2005). Speech pathologists implementing multimodal communication strategies ideally aim to increase the person's competence and confidence in not only using multiple modalities for communication, but also choosing and switching between modalities for different purposes to meet his or her communication needs across situations. Reliance or proficiency in only one modality for communication might leave a person vulnerable to breakdowns in communication across a range of communication contexts (SPA, 2012, pp 8-9).

- There is nothing to stop an individual from using natural gestures, signs language and PECS (for example) for routine requesting, choice making etc. Concurrent access to FCT, however, may provide a pathway whereby improved literacy and motor planning can lead to greater communicative freedom in the future.

Communication Rights

Lines 45 -58 ASHA recognizes the human right of communication, as expressed in the United Nations Convention on the Rights of Persons With Disabilities (UNCRPD; United Nations, 2006), the Universal Declaration of Human Rights (UDHR; United Nations, 1948), the International Communication Project (2014), and the Communication Bill of Rights by the National Joint Committee for the Communication Needs of Persons With Severe Disabilities (NJC; Brady et al., 2016). FC is a technique that involves the person with a disability being dependent upon a "facilitator" to compose a message. The use of FC or other facilitator-dependent techniques (e.g., Rapid Prompting Method [RPM]; see ASHA's Position Statement on RPM [ASHA, 2018]) is not consistent with the communication rights of autonomy and freedom of expression because the messages do not reflect the voice of the person with a disability but, rather, reflect the voice of the "facilitator". It must not be assumed that messages delivered via FC or any other facilitator-dependent technique (e.g., RPM) reflect the voice of the person with a disability.

- The suggestion that individuals' communication rights are best served by restricting the strategies professional clinicians are allowed to offer them is ludicrous.
- If, as argued under "Systematic Review Comments", research discrediting FC is not itself creditable, individuals should not be denied access to communication simply because an administrative decision has limited options available to professional clinicians.

Do you consider the information presented in the "Systematic Review of FC" section of the statement to be current and suitable for the purposes of the position statement?

(Yes/No)

No

Systematic Review Comments

Limitations of Schlosser et al. (2014)

1. Not peer reviewed

- Schlosser et al. (2014) was published as “ISAAC governance material” in the ISAAC journal AAC, without peer review. This is ironic, as the authors had stressed the importance of peer review in their selection of documents. I agree with Schlosser, Wendt, and Sigafoos (2007) that: “a bias through the exclusion of unpublished literature may threaten the validity of the systematic review” (p. 141). However, lack of peer review places a greater responsibility on the reader to exercise their own judgement. The ASHA ad hoc committee must make itself very aware of the limitations of Schlosser et al. (2014).

2. Not a systematic review

- Schlosser et al. (2014a, p.361) notes that approximately 60% of documents identified through the search process were evaluated by two independent raters, apparently exceeding the quality standard (20-30%) set by Schlosser et al. (2007, p.144). Remarkably, however, this process applied only to the coding of material for inclusion/exclusion, not to extraction of data for evaluation and synthesis. No coding categories are provided to guide data extraction, no explanation is given of the process behind the narrative ‘appraisal’ and ‘conclusions of the committee’ reported for the included studies, and no information is available regarding inter-rater agreement or dispute resolution at the evaluation stage. Instead, the review offers a narrative synthesis based on concurrence among reviews of FC, and concurrence of primary studies with the reviews.
- Schlosser et al. (2014) would not be admitted as evidence under the ASHA hierarchy, https://www.asha.org/Research/EBP/Assessing-the-Evidence/ , which rates “meta-analysis of randomized controlled trials” at the highest level of evidence but makes no reference to narrative reviews of quasi-experimental studies.

3. Only one synopsis and four primary studies are reviewed. Exclusion criteria are not explicitly stated

- Schlosser et al. (2007) asserts that the inclusion and exclusion criteria for a review should be stated a priori, to minimise scope and selection bias. The inclusion/exclusion criterial outlined in the “Method” section of Schlosser et al. (2014) implies that 98 documents were reviewed. In fact only five studies were actually reviewed by Schlosser et al. (2014). Two additional review studies are nominally included, however, analysis was limited to the observation that they identify no additional “level one” primary studies, and that their conclusions are consistent with Probst (2005). Clearly additional exclusions were subsequently applied according to criteria not discussed under ‘Method’, but introduced in the guise of analysis at a later stage of the report.

4. Only experimental research is reviewed

- Schlosser et al. (2014a) asserts that: “In order to determine the author of messages, an experimental design was required” (p.361). This resulted in exclusion of all documents not identified as level one evidence. No attempt is made to justify this position.
- Any suggestion that “scientific” means “experimental” belongs in the middle of last century. The current position is that:

  > “The experiment is not a clear window that reveals nature directly to us. To the contrary, experiments yield hypothetical and fallible knowledge that is often dependent on context and imbued with many unstated theoretical assumptions. Consequently, experimental results are partly relative to those assumptions and contexts and might well change with new assumptions or contexts” (Shadish, Cook and Campbell, 2002, p29-30).
- Alternatives to experimentation may be sought for a range of reasons, including: “fear of changing the phenomenon being studied in undesirable ways” (Shadish et al., 2002, p99), or because insufficient preliminary work has been done to develop causal theories for investigation; to describe the target population, treatment, or setting; or to develop appropriate outcome measures. Shadish et al. (2002) observes that: “Premature experimental work is a common research sin” (Shadish et al, 2002, p.99). It is certainly inappropriate in the case of FC, for which no clear definition exists of the “person, setting, treatment, and outcome constructs of interest” (Shadish et al., 2002, p.66). A broader research program is required to establish this information, which is needed before experimentation may proceed.

5. Inadequate attention to plausible rival hypotheses

- In quasi-experiments, the researcher has to enumerate alternative explanations one by one, decide which are plausible, and then use logic, design, and measurement to assess whether each one is operating in a way that might explain any observed effect” (Shadish et al., 2002, p14). Critics of FC have endlessly tested only one rival explanation – that of facilitator control - then declared the matter closed.
- For Shadish et al., (2002): “validity is not a property of methods but of inferences and knowledge claims” (p.480) and “threats are better identified from insider knowledge than from abstract and nonlocal lists of threats” (p.474). This position is not compatible with the almost total exclusion of “insider” knowledge exercised by Schlosser et al. (2014a).

6. The validity of the outcome measure is unexamined

- Schlosser et al. (2014) does not explicitly identify how authorship is to be measured for the review, although, on the basis of the studies ultimately included an approach similar to that of Probst (2005) was presumably adopted: “communicative performance (under facilitator-blind and facilitator-non-blind conditions), in terms of percentage of correct responses” (Schlosser & Wendt, 2008, p. 82). The validity of this outcome measure is neither discussed nor defended by Schlosser et al. (2014), nor by the authors of included studies.
- The American “Standards for Educational and Psychological Testing”, jointly developed by the American Educational Research Association (AERA), the American Psychological Association (APA), and the National Council on Measurement in Education (NCME) (2014) identifies two major threats to the construct validity of psychological tests.

- The first is construct underrepresentation (or construct deficiency) in which a test is too narrow and measures less than its proposed construct. In the context of FC research, it may be argued that tests based exclusively on a subject's ability to produce a 'typical' response to a researcher's agenda provide no means of assessing other forms of communication, such as self-motivated communication on topics important to the communicator.
- The second major threat is construct-irrelevant variance (or construct contamination), which occurs when "test scores are affected by processes that are extraneous to the test's intended purpose" (AERA et al., 2014. p12). There are two basic types of construct-irrelevant variance: construct-irrelevant difficulty, which occurs when "aspects of the task that are extraneous to the focal construct make the task irrelevantly difficult for some individuals or groups" (Messick, 1995, p742), resulting in lower-than-appropriate scores, and construct-irrelevant easiness, which "occurs when extraneous clues in item or task formats permit some individuals to respond correctly or appropriately in ways irrelevant to the construct being assessed" (Messick, 1995, p743), resulting in higher-than-appropriate scores.
- It may be argued that expecting autistic FC users to respond to a researcher's agenda (e.g. to pass messages) imposes construct-irrelevant difficulty, as it requires skills additional to those needed for self-motivated communication. Some of those skills are known to be problematic in autism: For example, relatedness and joint attention difficulties may interfere with an individual's ability to learn from the goal-oriented behavior of others (Rogers and Bennetto, 2000). Similarly, perceptual abnormalities may lead to weak central coherence and "context-free" processing (Happe & Frith, 2006) – factors likely to be problematic for selection of context-appropriate actions such as message passing.
- It may also be argued that the potential for cuing afforded by physical contact with a facilitator may result in construct-irrelevant easiness. Research has demonstrated that facilitator influence is more likely in the context of closed questions with simple answers (Wegner Fuller and Sparrow, 2003) and at higher levels of physical support (Kezuka, 1997) – conditions that characterize most of the studies included by Schlosser et al. (2014a) and Probst (2005). Conclusions drawn from such research generally cast FC users as passive intermediaries in the communication process, as emphasized by references to "facilitator control" (e.g. Schlosser et al., 2014, pp. 359, 363, 364, & 365), rather than 'facilitator influence'. The concept of 'control' does not take account of the possibility that at times - for example, when unsure what is required of them - FC users may actively and intentionally seek cues from their facilitators.

7. Experimental results that "don't fit" are disregarded

- While limitations are identified in respect of all four primary studies, these are minimally elaborated and (in common with earlier reviews of FC) are taken to undermine only those findings that may be interpreted as supportive of FC. For example, the potentially positive findings of one primary study (Schiavo et al., 2005) are dismissed on the basis of a very cursory discussion of "appraised shortcomings", while those of another (Perini et al., 2010) are accepted, despite incomplete reporting of methods and of results. The report explicitly states that this conclusion is reached because the findings concur with other reviews and policy statements.

- Findings inconsistent with other reviews and policy statements are not merely set aside as unsound: they are effectively wiped from the record, leaving all four primary studies to be reported as: "robust evidence that FC is not a valid technique" (Schlosser et al, 2014a, p.365-6).

8. Use of inappropriate "hierarchy of evidence", designed for clinical decision making, not research

- Regarding level one studies, five were excluded due to temporal constraints, one to linguistic constraints, and 43 on the basis of an unconventional "hierarchy of evidence" (the 6S model) that dismisses primary studies that have been subjected to review, and reviews that have been subjected to synopses. The 6S model and its predecessors appear to have been devised for the convenience of busy practitioners seeking to integrate research into their clinical decision-making, in keeping with models of Evidence Based Practice. Its relevance for a research context is not discussed.
- Under the 6S model a synopsis of Probst (2005), written by Schlosser and Wendt (2008), becomes the principal source for Schlosser et al (2014). This is taken to capture data from Probst (2005) and from the 42 primary studies reviewed in that study. However, Schlosser et al. (2014) fails to mention shortcomings identified by the synopsis. Probst (2005) was deemed to only partially met standards for: reporting search terms; predefining inclusion and exclusion criteria; predefining data extraction and coding categories; and predefining criteria to judge the quality of included studies. It did not meet standards for data extraction by more than one rater or provision of inter-rater agreement data, nor for operationalized criteria for judgement of effectiveness.

9. Peer reviewed analysis and commentary are excluded

- Material assigned to "inclusion level four" was excluded as "anecdotal reports", however it should be noted that commentary and appraisal of empirical research were also deemed to be level four evidence because they are "essentially perspectives of individuals" and "could not, therefore, be accepted as scientific evidence" (Schlosser et al., 2014, p.365).
- Again, it would be good to be given more information about how the authors of Schlosser et al. (2014) define "scientific". Exclusion of level four evidence seems to imply a belief that experimental results are free from theory and from the perspective of researchers – a position not held by scientists, at least since Quine's landmark 1951 paper, "The two dogmas of Empiricism". Unless Schlosser et al. (2014) is suggesting that the "discussion" and "conclusion" sections of reports should be disregarded and only the results considered, it must be recognized that scholarly comment on the results of research studies should not be excluded. As recognized as long ago as 1963: "Presumably, at any stage of accumulation of evidence, even for the most advanced science, there are numerous possible theories compatible with the data, particularly if all theories involving complex contingencies be allowed" (Campbell and Stanley, 1963, p. 36).
- Shadish et al. (2002) notes that researchers "may fail to pursue all the alternative causal explanations [for experimental results] because of a lack of energy, a need to achieve closure, or a bias toward accepting evidence that confirms their preferred hypothesis" (p.30). This makes it particularly important that reviewers consider the possible alternative interpretations of experimental data, along with evidence from alternative

research designs, unpublished studies, clinical experience and personal accounts, and from research that "did not focus on FC" or mentioned FC "only in a tangential manner".

10. Research using alternative designs (that is, most twenty-first century research) is excluded.

- As noted at point 3 (above), the inclusion/exclusion criterial outlined in the "Method" section of Schlosser et al. (2014) implies that 98 documents were reviewed. These were assigned to one of four "levels of inclusion", and everything not deemed "level one" was summarily excluded. Exclusion of level four material is discussed at point 9. Level two and three studies were excluded because: "it was evident that the authors of these studies failed to pre-establish authorship by their participants" (Schlosser et al., 2014, p. 365).
- While some level two and three studies do focus on issues other than authorship (e.g Kasa-Hendrickson, Broderick, & Hanson, 2009; Wilson, de Jonge, de Souza, & Carlson, 2014), others address authorship directly, using approaches such as statistical analysis of textual data (Bernardi & Tuzzi, 2011; Tuzzi, 2009); video analysis of experienced FC users in naturalistic contexts (Bigozzi, Zanobini, Tarchi, Cozzani, & Camba, 2012); and a combination of fine-grained video analysis and eye tracking (Grayson, Emerson, Howard-Jones & O'Neil, 2012). The suggestion that "these studies were predicated on the assumption that the participants … were the authors of the messages generated" (Schlosser et al., 2014, p365) is quite simply incorrect, strengthening the impression that material was excluded without due consideration of content.

11. Grey literature, clinical reports, and the voices of stakeholders are excluded

- Schlosser et al. (2007) condemned "publication bias", which occurs when the published research is systematically unrepresentative of the population of completed studies, yet contrary to submission guidelines issued by ISAAC in 2013 (https://www.isaac-online.org/wordpress/wp-content/uploads/ISAAC-E-News-March-2013-Final.pdf, p. 9), Schlosser et al. (2014) only included peer reviewed material. This resulted in exclusion of 320 documents, including personal submissions from stakeholders.
- Exclusion of unpublished material is especially significant in relation to a contested issue such as FC, where bias in peer review is reported (e.g. Taylor, 1996) and even encouraged (Mostert, 2015).
- Exclusion of personal submissions eliminates consideration of the tacit knowledge held by speech pathologists, occupational therapists and other clinicians who use the technique, along with the lived experience of families, teachers, carers and FC users who had responded to ISAAC's changed submission guidelines. Models of Evidence Based Practice (EBP) acknowledge the role of clinical experience as "the crucial element that separates evidence-based medicine from cookbook medicine and the mindless application of rules and guidelines" (Haynes, Sacket, Gray, Cook, & Guyatt, 1996, p.197).

12. Research that may help formulate plausible rival hypotheses for experimental results is excluded

- Material not directly referring to FC, but which may suggest possible alternative explanations for experimental results, was excluded. (E.g. material addressing sensory, movement, and attentional differences in populations from which FC users are drawn. See comments under “Additional Feedback”, below).

Other “Systematic Review Comments”

Line 73-74: Proponents of FC state that the technique reveals previously undetected literacy and communication skills in people with autism and other disabilities.

- See comments on hyperlexia under “additional feedback”

Line 74-75: … these statements are made only on the basis of anecdotal reports and testimonials.

- There are a significant number of qualitative and mixed studies to support FC. These are not anecdotal reports and testimonials. See comments on the value of alternative research designs under “Position Comments”
- This is not to devalue anecdotal reports. It is essential, and a central tenet of EBP, that clinical reports and reports from stakeholders are embraced to inform progressive research programs and develop new hypotheses for investigation and testing.

Line 61-71: A recent systematic literature review of FC (Schlosser et al., 2014; updated in 2018)

- This “update” has not been published and is not publicly available. It seems inappropriate to request feedback on a document that cannot be accessed.

Line 70: and clinical assessments

- What clinical assessments? Schlosser et al. (2014) excludes consideration of clinical evidence.
- If this is a reference to clinical assessments using message passing, there is absolutely no evidence that message passing is a valid test of communicative competence.
- If clinical evidence is to be examined, evidence from clinicians who use FC successfully with their clients must also be taken into account.

Line 70-71: demonstrates that messages delivered using FC are authored by the “facilitator” and not by the person with a disability.

See previous comments related to lines 15-18.

Lines 75-77: Clearly, FC is a pseudoscience (Finn, Bothe, & Bramlett, 2005; Lof, 2015) or “junk science” (i.e., faulty information or research used to advance specific interests; Agin, 2006)

It would have been considerably more helpful for the committee to advise their definition of “science” rather than “pseudoscience”. It would appear that they equate “science” exclusively with “experimentation”. This belief may have been understandable mid last century, but it is certainly no longer accepted by the scientific community as seen in comments from the NRC (2002) and Shadish et al. (2002), discussed under “Position Comments”. The position has been clouded by legislation covering education research since 2002. That cannot be taken as the position of the scientific community.

The NRC report contrasted attitudes from "the research community" with those "crafted in the political milieu" (National Research Council, 2002, p. 21):

> Unprecedented federal legislation exalts scientific evidence as the key driver of education policy and practice, but - here's the rub - it also inches dangerously toward a prescription of methods and a rigid definition of research quality. … Educational researchers, like other researchers, worry that the good intentions underlying the SBR [Scientifically Based Research] movement will go awry, that narrow definitions of research or science might trivialize rather than enrich our understanding of education policy and practice, and that the splendors of unfettered scholarship will be eroded by creeping tides of conformity and methodological zealotry. (Feuer, Towne, and Shavelson, 2002, p. 4).

Revisiting the issue two years later, the authors confirmed that, in some cases at least, their fears had been well founded:

> "In the best case scenario, states have integrated the SBR provisions into their accountability systems by using evidence as a key component of their technical assistance to schools that need the most help. In the worst case scenario, states are simply developing lists of 'evidence-based' programs that school districts can adopt with federal funds" (Feuer, Towne, and Shavelson, 2004, p.39-40).

This is cookie-cutter intervention.

Line 77-83: which has several negative and harmful consequences, in that it
a) is not an effective form of communication and does not provide access to communication;
b) denies the user's access to their human right of communication;

- see discussion under "comments about the FC definition" regarding harms.

c) costs time and money and, hence, reduces opportunities for access to effective and appropriate treatment;

- With respect to c), research into provision of alternative communication support for individuals who have had access to FC withdrawn due to the Queensland or ISAAC review may be informative.

d) supplants other forms of effective communication;
e) gives false hope to families of individuals with little or no speech; and
f) has been associated with significant preventable harms arising through false allegations of sexual abuse and mistreatment (Boynton, 2012; Chan & Nankervis, 2014; Wombles, 2014).

- Re d), e) and f), see discussion under "comments about the FC definition" regarding harms.
- The sources cited in f) were excluded by Schlosser et al. (2014) as "level four evidence". Also excluded were extensive accounts of benefit from FC.
- It is acknowledged that there is peer reviewed commentary and anecdotal evidence of harm. In many cases, it appears that harm could have been avoided if appropriate "best practice" guidelines had been followed. This is largely reliant on professional oversight.
- There has been no attention paid by the authors of this draft Position Statement to the benefits of FC, some of which are documented in peer reviewed studies and commentary (excluded from consideration by Schlosser et al., 2014 as levels 2, 3 and 4 evidence)

- Anecdotal sources of information have been diligently ignored by the committee, were ignored by the ISAAC reviewers and, although considered, appear to have been largely excluded from the final 1994 Technical Report. It is time these voices were heard.
- Supplementary Appendix A of Schlosser et al. (2014) lists some 368 documents submitted to ISAAC by members for the review. (This is not a complete list – my own submission, though acknowledged by the ISAAC office when submitted, is not listed.) If this archive has been retained, perhaps (with permission from the authors) it may be made available for consideration by ASHA.
- Given the total disregard of that material by the ISAAC reviewers (typical of reviews of FC), it seems unlikely that stakeholders will continue to offer assistance to reviews. Recent approaches to this topic appear deliberately designed to increase the "science-practice gap", and in doing so they are radically increasing risk by dismantling professional oversight of practice.

Do you agree with the recommendations?

(Yes/No)
No

Recommendation Comments

Lines 91-92: Speech-language pathologists (SLPs) are autonomous professionals who are responsible for critically evaluating all treatment techniques …

- The draft Position Statement, if adopted, would take decisions out of the SLPs' hands. They must be free to exercise their professional judgment in deciding the most appropriate intervention to select in order to meet the specific needs of individual clients. This draft position statement does not respect their autonomy.

Line 94-96: SLPs should be mindful of their own legal and ethical responsibilities (ASHA, 2016) in not doing harm and should be aware of their potential legal risk for liability in relation to the use of FC.

- The ASHA code of ethics states that: "Individuals shall not misrepresent research and scholarly activities …" (Principle of Ethics 3.C). By failing to report threats to the validity of experimental studies; evidence of successful communication produced under experimental conditions; and the existence of non-experimental research supportive of FC, the draft Position Statement misrepresents research and as a result the committee are in danger of breaching the ASHA code of ethics..

Line 98-101: The substantial and serious risks of FC outweigh any anecdotal reports of its benefit. The scientific evidence against FC, evidence of harms of FC, and potential for future harms to people who use FC and their families cannot be ignored in clinical decision making

- See discussion under "Systematic Review Comments" regarding the evidence.
- See discussion under "comments about the FC definition" regarding harms.
- The assertions made in lines 98-101 must be recognized as unsubstantiated. No attempt has been made to weigh harm against benefits of FC. Advocates argue that risks can be managed and that, for those individuals who are helped by FC, benefits generally outweigh well managed risk. The risks of not providing communication support must also be taken into account.

- In a 2012 review of FC in Queensland, Australia reported:

  > If the department does not agree to phase out FC, its current policies and procedures relating to FC only require minor modification. … we were quite impressed with the manner in which the procedures address most of the existing concerns about FC. Again, however, what will be important is compliance with the policy, as well as stringent monitoring of that compliance (Mazerole and Legosz, 2012, p9).

  The point must again be made that, if the draft position statement is adopted, it will result in the dismantling of existing safeguards, professional support and oversight, thus significantly increasing risk.

Line 101-103: SLPs who use FC—despite being informed of and knowing these harms and risks—could face additional risks in terms of their own liability in the event of harms arising to people with disabilities or their families related to use of FC.

- This is a clear example of scare tactics, the effect of which will be to remove autonomy from SLPs, dismantle professional oversight of FC practice, and thus increase risk.

Line 105-114: SLPs have a responsibility to inform and warn their clients' parents, guardians, and teachers who are using or are considering FC that

a) decades of scientific research on FC has established with confidence that FC is not a valid form of communication,

b) messages delivered by FC do not reflect the voice of the person with a disability,

c) FC does not provide access to communication

d) the use of FC is associated with several harms to individuals with disabilities as well as their family members or teachers, and

e) the ASHA position on FC is that it should not be used.

- See discussion under "Systematic Review Comments" regarding the scientific evidence against FC.
- See discussion under "comments about the FC definition" regarding harms.
- Regarding the responsibility "to inform and warn" - I am only able to speak from personal experience, but note that evidence against FC has always been discussed at some length in facilitator training workshops I have attended. "Best practice" is focused on minimizing the identified risks. Training and efforts to maintain "best practice" will be dismantled if professionals are directed not to be involved.

116-125: SLPs also have an ethical responsibility to inform clients' parents, guardians, and teachers of evidence-based treatments for communication for individuals with communication limitations and to advocate for these treatments. Several systematic literature reviews have demonstrated the value of communication interventions for individuals with severe intellectual and developmental disabilities (Allan et al., 2017; Brady et al., 2016; Iacono et al., 2016; Logan et al., 2017; Romski & Sevcik, 2016; Snell et al., 2010; Walker & Snell, 2013). See the Augmentative and Alternative Communication evidence map (ASHA, n.d.-a) for summaries of available research on this topic and the Practice Portal on Augmentative and Alternative Communication (ASHA, n.d.-b) for information on a variety of evidence-based intervention approaches.

- It is notable that, in a draft position statement addressing FC, only one empirical study of FC is cited compared with so many citations regarding alternatives.
- It has never been suggested that FC is a suitable strategy for a large number of individuals. It is merely one of a range of strategies that should be available for Speech-Language Pathologists (SLPs) to choose from in their efforts to address their client's needs. As Rosemary Crossley has said, FC " *… is not an ideal strategy. It is the strategy you use when you don't have a better one*". (Crossley, 1994, p7). This point was also made in the ASHA 1994 Technical Report.
- FC should be offered to individuals whose communication needs cannot be met by other strategies. It's use does not preclude use of complementary strategies.

127-129: ASHA strongly supports continued research and clinical efforts to develop scientifically valid methods for developing and enhancing the authentic and independent communication and literacy skills of people with disabilities.

- Why has there been no discussion of the 1994 research recommendations? Research based on such recommendations is deliberately excluded from consideration in Schlosser et al. (2014), the only empirical study referred to by the ASHA committee.

131-134: ASHA's position on FC is consistent with as many as 16 other national and international professional organization statements (see International Society for Augmentative and Alternative Communication [(ISAAC)], 2014; Speech-Language and Audiology Canada, 2018).

- According to ASHA's own hierarchy of evidence (https://www.asha.org/Research/EBP/Assessing-the-Evidence/) "expert committee reports" are the lowest form of evidence, ranking below the "well-designed non-experimental studies" that have been excluded from consideration by Schlosser et al. (2014). The ASHA draft report appears to deny the existence of any such studies.

What impact, if any, do you think the proposed position statement on FC will have on your work or the work of others in supporting communication?

Where academic anti-FC sentiment has resulted in the dismantling of professional support structures (as in Queensland, Australia), practice has become fragmented, ill-informed, and unregulated. This brings with it a correspondingly increased risk of harm that must be acknowledged and owned by those seeking to shut down the FC debate.

The cost of failure to support individuals whose only option for communication access is FC is impossible to estimate at this stage.

In part, it may be counted as a lost opportunity for a more positive approach to support.

It may be counted as increased use of restrictive practices, and the implications that has for society in general.

It may be counted as loss of opportunity for more meaningful relationships with loved ones.

Without FC, we may never know what has been lost, as we may never know the potential of the people who have been silenced.

Is there any other information that you need in order to be able to implement the ASHA FC position statement?

If so, write your information needs here.

SLPs need to be informed of the full range of research.
Clinical expertise needs to be respected, as per EBP
Stakeholder's voices need to be heard.

It should be noted that four of the seven members of the current ASHA committee on FC have strongly and publicly expressed opposition to FC (e.g. Schlosser et al, 2014a; Hemsley & Dan, 2014; Travers, Tincani & Lang, 2014; Tostanoski, Lang, Raulston; Carnett; and Davis, 2014; Sigafoos and Schlosser, 2012; Lilienfeld, Marshall, Todd, & Shane, 2015; Shane, 1994). The remaining three members of the committee do not appear to have publically expressed their opinion on the topic. It is unclear whether they have clinical experience of FC.

Section I.G of the ASHA operating procedures states that nominations for the committee will be "based on history of clinical work, research, and/or knowledge related to FC and RPM, including presentations and publications". Section II.E states that "The Committee follows a process to ensure that a diverse range of members are recommended to the Committee on Committees for appointment consideration".

It can only be assumed, given exclusion of any practising facilitators and inclusion of four stanch critics of FC, that ASHA has committed in advance to publishing a position statement that is highly critical of FC. If so, that information should be conveyed to all of those who would be affected by the decision, without pretense that the decision has been based on 'science".

Additional Feedback

Advances in understanding movement disorder

Dr Barry Prizant was a member of the sub-committee which authored ASHA's 1994 Technical Report. In the same year he co-authored a chapter (Prizant, Wetherby & Rydell, 1994) of a book edited by a member of the current ASHA committee on FC (Shane, 1994).

The book was largely devoted to debunking FC, although the greatest criticism offered by Prizant et al. (1994) was that: "Persons with autism are assumed to suffer from a primary motor disability, which can not explain patterns of cognitive processing reviewed [in the book chapter]." (p.135).

Ironically, the characteristic social-cognitive learning style described by Prizant et al in 1994 anticipated research that, with a few years, would link sensory and motor differences to the development of cognitive processing differences in autism. In 2000, two of the authors of Prizant et al (1994) edited their own book (Wetherby and Prizant, 2000). Chapters in that book described theoretical models of cognitive development in autism, under the influence of sensory and movement issues. These theories were based on, and tested by, rigorous scientific investigation. As FC is not mentioned in this book, it – along with the bulk of research on sensory and movement differences in autism – is excluded from consideration by Schlosser et al, (2014).

As summarised by Mirenda (2008), more recent research has supported these findings.

Advances in understanding hidden literacy

Despite the alternate view expressed by his editor (Shane, 1994, p.24), Prizant *et al* (1994) suggested that hyperlexia may provide a key to understanding FC, and to interventions that may increase comprehension and analytical processing:

> … if research supports the validity of FC in individual cases, the research literature on hyperlexia may be an important source for understanding the motivation and, possibly, the ability of some individuals to intentionally use typed output as an expressive mode. In such cases, the generativity and situational relevance of typed output should be examined, for if hyperlexic abilities underlie instances of typed output through FC, generativity and relevance may be limited. However, in our experience, we have observed parallels in hyperlexia and echolalia, in that early occurring patterns may reflect more rote production with limited comprehension, with movement towards more intentional production demonstrating increased comprehension and analytic processing (Prizant *et al*, 1994, p. 133-4).

A recent review described hyperlexia as: "the co-occurrence of advanced reading skills relative to comprehension skills or general intelligence, the early acquisition of reading skills without explicit teaching, and a strong orientation toward written material, generally in the context of a neurodevelopmental disorder" (Ostrolenk, d'Arc, Jelenic, Fabienne Samson. & Mottron, 2017, p.134). The review found that: "hyperlexia, or a hyperlexic-like profile, characterises a substantial portion of the autistic spectrum" (p.134). Similar to Prizant et al. (1994), Ostrolenk et al. (2017) observed that:

> Just as echolalia constitutes an initially non-communicative developmental step in the access to language specific to autism, hyperlexia may actually be more than non-communicative meaningless reading, but rather constitute a developmental step towards reading comprehension and possibly written and oral communication (p.146).

Clearly this may be a fruitful avenue for future research into FC. It should be noted, however, that the review does not mention FC and would therefore have been excluded from Schlosser et al. (2014).

Ostrolenk et al. (2017) suggests that:

> The pattern of dissociation between decoding abilities and comprehension evident in hyperlexia results from the particular characteristics of autistic perception and learning modalities, the understanding of which is essential to adapt education and pedagogy to the special needs of autistic individuals (p.146).

Similar understanding may be needed to explain why FC users find message passing so difficult.

Further, interventions targeting hyperlexia, may potentially be beneficial for FC users if the programs can be adapted to their communication needs. Ostrolenk et al. (2017) note that: "A recent fMRI study showed that a strength based reading intervention could lead to improved reading comprehension in autistic children through changes in their brain function (Murdaugh et al., 2015), which could potentially lead to increased communication" (p.146).

FC users will not, however, be able to participate in such interventions if their communication strategy is not recognised.

Intervention

One chapter in Wetherby and Prizant (2000) emphasised "the importance of participation in shared cultural events and the situational relevance of utterances" (Wetherby, Prizant and Schuler, 2000, p128):

> Rather than focus on the rote reproduction of language forms that may be irrelevant to the communicative contexts at hand, intervention efforts need to emphasize communicative function, contextual relevance, and cultural belonging (Wetherby, Prizant and Schuler, 2000, p128).

Another chapter made the following observation regarding interventions most likely to produce real benefit in the cognitive development of autistic individuals:

> In evaluating the effectiveness of interventions, it is important that progress is measured in terms of meaningful outcomes, such as improvements in the quality of the lives of the children and their families involved in the intervention and the ability of children to experience a greater sense of efficacy by engaging in social interactions in a more mutually satisfactory way. To accomplish such gains it is important that intervention efforts do not solely target deficits within the child but target daily living and learning environments as well as communication partners, including parents, siblings and peers, to create the types of contexts that are more responsive and conducive to communicative initiations. By creating contexts for joint action and joint attention … and by coaching peers and adults in how to sustain interactions, a greater sense of communicative efficacy is established. … Such an emphasis will reduce the transactional secondary effects of more primary disabilities, which may be more devastating in the long run than the initial limitations exhibited by the child. Ultimately, the individual's competence in social interaction, in developing relationships, and in the capacity to cope with stress using flexible communicative strategies will determine the level of independence that he or she can have beyond early childhood. (Prizant, Wetherby, & Rydell, 2000, p134-5.)

The implications of difficulties with praxis and imitation, common in autism and arguably more pronounced among autistic FC users, may be considerable. Another chapter in Wetherby and Prizant (2000) described movement as the messenger of emotion, and suggest that coordinated movements between social partners are essential for emotional connectedness. A child unable to match caregivers imitatively and reciprocally cannot learn to experience emotional contagion and self-other correspondence:

> As development occurs, the degree of imitative ability that develops in autism varies from one person to the next because of individual differences in development and

> treatment. The child with autism may learn to develop many movements, but the ongoing praxis problems prevent the automatic, smooth, synchronous, continuous motor matching of a partner. The continuing problems in imitation involving timing, speed, grading, and movement impede the establishment of emotional synchrony, and these two components lie behind the "relatedness" deficit in autism. (Rogers and Bennetto, 2000, p100.)

Rogers and Bennetto noted that intervention should aim to create moments of relatedness through carefully constructed interpersonal experiences. They suggest that the potential for increased synchrony improves as coordination of movements improves.

> … as long as the environment provides continuing experiences of interpersonal matchings and as long as the person with autism has not "given up" on ever connecting with the social world (Rogers and Bennetto, 2000, p100).

It should be noted that Rogers and Bennetto (2000) makes no reference to FC and is thus excluded from consideration by Schlosser et al. (2014). It does not, however, take much imagination to extend the concepts outlined in that chapter to FC. Perhaps the proximity and physical contact between facilitator and communicator improves synchrony, joint attention, and the experiences of emotional contagion. Further, access to a strategy that allows communication appropriate to context has powerful potential to promote functionality, relevance, and inclusion.

These suggestions are, of course, speculative. They may form the basis for future research, however significant observational study is likely to be needed before experimental research into these questions would be appropriate.

What does appears clear from these insights is that confrontational testing, including message passing tests in highly contrived settings, may challenge the emotional support that is emphasized in FC.

June 11, 2018

Vaish Sarathy

vaishnavisarathy@gmail.com

I am the parent of a child with multiple disabilities, severe visual and motor issues. He also happens to be non-speaking. Over the last decade, we have tried almost every communication method there is: including PECS, AAC (including 3 different apps on the Ipad). I can confidently say that I have given it my all. And... unfortunately, none of these worked. His vision and motor skills came in the way every time.

When we started using letterboards (via RPM) for academics, everything changed. My child was slowly but surely able to access answers. His school has been using letterboards, so there is no question of parent or practitioner bias. He has used letterboards with 5 different people, most of whom have not even heard of RPM , and it works.

I am disappointed and heartbroken that ASHA would choose to invalidate the experiences of hundreds of kids throughout the world, and have not contacted or observed even one successful letter-boarder.

This reeks of bias. I request you from the bottom of my heart to end this discrimination, to withdraw your hasty response, to go observe these kids with an open mind, to try to learn the method if you really want to study it. Empirical evidence is also evidence.

And finally, to apologize to the multitude of children who can't speak for themselves, who you have just tried to silence forever.

Keep ASHA on the right side of history. Non-speaking does not equal non-thinking.

Sincerely,
A parent of a child that really needs your support (not condescension)

June 11, 2018

Christopher Rosien

hyperchris@me.com

To the ASHA Board regarding the proposed position statements on FC and on RPM. I wish to share this response as a parent ...

I agree it's all about the evidence.

I was so skeptical when my son Dan was "starting to type some words" with his SL. I sent a friend along to observe and find out what was really happening. She reported that the SL was simply restraining his impulsivity and instituting a rhythm to his tapping. He was handling spelling games with no assistance and when it came to words and phrases he was really doing it provided he could get some physical feedback.

Over time Dan's SL and then my friend with some training each moved the support away from his typing arm. They started at the elbow braking his movements but then it was at his bicep, then shoulder, back of neck and eventually all the way over to the other shoulder and that is just pinching his shirt! That took about a year but we have tons of footage showing the progression.

My son started this at age 14 and a whole new world opened up for all of us. From his iPad we heard "I love you" for the first time and learned just how brilliant he is. After preK through 10th grade in SDCs, this Fall Dan takes his first college courses at age 18. That's how much intelligence was locked away behind his communication barrier.

We have to presume competence and allow for these approaches. Yes they need to be rigorous in their approach and yes there will be setbacks but these things are true of every therapy.

All are welcome to connect with us to ask Dan questions or to see the video of his progression. I took great care to show his independence so that we had evidence for his school and others.

He'd love to share it with you!

Thank you ...

Christopher Rosien
Dan's Dad

June 28, 2018

Elizabeth Vosseller, MA, CCC-SLP

elizabeth@growingkidstherapy.com

To the Board of Directors:

I am writing to you to ask that you withdraw the proposals from the Ad Hoc committee on FC and RPM. The members of this committee have a longstanding public record of trying to discredit the use of FC, RPM and other forms of typing or spelling as a form of communication. A review of their articles, Twitter posts and other public commentary ridiculing nonspeakers makes their bias abundantly clear

I have been a SLP and ASHA member for 24 years. In my career as a SLP, I have specialized in autism and complex communication disorders through my work at: Children's National Medical Center in Washington DC; as a professor and clinical supervisor at The George Washington University – teaching and supervising in both speech-language pathology and later in special education; and as the owner of a private practice, Growing Kids Therapy Center. I currently work exclusively with nonspeaking individuals who spell or type to communicate.

In Speech Pathology 101 we learned that speech and language are two different functions and that if speech is impaired, it does not necessarily mean that language is impaired. Neuroanatomy and physiology teach us that the primary centers of language are Wernicke's and Broca's areas and that speech occurs as a complex motor process involving the primary and supplementary motor cortex. Individuals who have childhood apraxia of speech, a neurological speech sound disorder that affects the planning and programming of the motor movements required for speech sound production (ASHA, 2007), may have difficulty producing spoken language without any impairment in language. A growing number of studies indicate a high comorbidity of autism and apraxia, as high as 63.6% (Tierney et al., 2015)–that is, nearly two-thirds of children diagnosed with autism also have apraxia.

In other explanations of apraxia, ASHA (2007) has further stated, "Individuals with apraxia of speech know what words they want to say, but their brains have difficulty coordinating the muscle movements necessary to say all the sounds in the words. As a result, they may say something completely different or make up words (e.g., "bipem" or "chicken" for "kitchen"). The person may recognize the error and try again—sometimes getting it right, but sometimes saying something else entirely. This situation can become quite frustrating for the person." Nonspeaking autistics present with patterns consistent with childhood apraxia of speech: difficulty imitating, initiating and inhibiting actions; poor sequencing and coordination of movements; errors in prosody; groping for proper articulatory positioning; better production of automatic speech than novel speech; uncoordinated speech-breath timing; frustration; and limited gains from traditional speech and language intervention.

The earliest documentation of autism by Leo Kanner (1943) and Hans Asperger (1944) both note clumsiness, awkward gait and motor irregularities in many of the autistics they first studied. There is a growing body of research documenting the motor differences in autistics. Focaroli et al. (2016) found that an early predictor of autism in infant siblings of children diagnosed with autism was delays in early motor skills. Researchers at Kennedy Krieger also observed limited fine motor activity, grasping and use of motor for object exploration in these infants (Klaus et al. 2014). In a meta-analysis of 83 studies related to motor and autism, Fournier et al., (2010) concluded that "motor deficits are a potential core feature of ASD" (p.1237).

Anne Donnellan and Martha Leary's work over the past twenty years has focused on documenting and describing sensory movement differences in autism. Using first-person accounts and experimental evidence from autism and other well-characterized motor disorders (e.g., Parkinson's), Leary et al. (1999, as cited in Robledo et al., 2012) define sensory and movement differences as a "difference, interference or shift in the efficient, effective utilization and integration of movement; a disruption in the organization and regulation of perception, action, posture, language, speech, thought, emotion and/or memory" (see also Hill & Leary, 1993; Donnellan & Leary, 1995; Leary & Hill, 1996; Leary & Donnellan, 2012; Robledo et al, 2012). To many autistics–both speaking and non-speaking–difficulty in planning and executing purposeful movement in speech as well as in other domains like pointing, responding to novel motor movement demands and initiating self-directed actions is *the most* disabling aspect of their disability (Robledo et al., 2012). Although experimental research on movement differences in autism is relatively new (compared to, e.g., putative social differences; Kanner, 1943), researchers are beginning to argue that because movement differences are objective and quantifiable and, the movement perspective on autism shows considerable promise (Torres & Donnellan, 2015).

Why is there a persistent belief that nonspeaking individuals cannot possibly have the language skills to communicate? Testing. All tests of language, academics, cognition, and intelligence require a motor response such as speech, pointing, gesturing, touching or manipulating objects.

If motor differences are at the core of autism, those with motor planning and control issues significant enough to affect speech will not be able to respond reliably to standardized testing. When an assessment is used that takes advantage of autistics' strengths (e.g., pattern-matching) and involved making responses that were familiar and well-practiced (e.g., fitting pieces into puzzles), Courchesne et al. (2015) showed that many minimally speaking or nonspeaking school-aged children's intelligence was vastly underestimated. In fact, a systematic evaluation of data by Edelson (2006) concluded that when appropriate measures of intelligence are used to account for the interference of autism, a significantly lower rate of intellectual impairment was found relative to rates commonly reported in the literature. Despite this finding, the practice of assuming significant intellectual impairment in nonspeaking individuals continues. During an IEP meeting after the team reported his poor performance on triennial testing, my client Ben spelled, "With all due respect, your tests measure my motor skills not my cognitive skills."

Although my 24 years of clinical experience and reading of the literature makes me confident that my nonspeaking autistic clients experience significant–almost unimaginable–motor challenges, what if I (and many others) are wrong? That is a possibility. But what if the motor perspective is right? If we ignore the implications of motor in autism and assume a lack of interest, motivation, ability, intelligence or desire to learn, how might we fail our nonspeaking clients? This conundrum is called the least dangerous assumption (Jorgensen, 2005). On the one hand, we can accept low standardized test scores as resolute fact, interpret out of control bodies as intentional behavior, and view limited speech as the extent of cognition. On the other, we can believe that testing does not account for all skills, that speech is not an indicator of intelligence, that motor differences can make regulation difficult, and that autistics–just like non-autistics–learn best when valued and will excel when challenged and supported. Both approaches are not without danger if we later learn our assumptions were incorrect. If we put our faith in the results of standardized tests and years later learn that those tests were not an appropriate way to measure a client's potential or ability, we will have failed to provide them with an appropriate education. If we provide an individual with age-appropriate instruction and later learn that we have overestimated their capabilities, we will also have erred. But to my mind, the latter option represents the least dangerous assumption: I will risk teaching too much and choose to believe that my clients are indeed capable every time.

Spelling gave this client the opportunity to participate in a college course at the University of Virginia.

Although the steps involved: assess, teach, shape, practice, and generalize are the basis of most of our intervention as SLPs there is one significant difference when teaching spelling or typing to communicate. The emphasis is on teaching motor skills, not cognitive skills or language, though all of the lessons I use to practice the motor skills are designed to provide content that is interesting, new, and age-appropriate. They may introduce new vocabulary or new concepts, but the presumption is that the client is capable of learning this material and of reflecting on it. The premise of spelling as a form of communication for nonspeaking individuals is that the core issue is motor and that despite motor planning issues for speech, language is intact. Acquisition of skills for letterboards can vary significantly – just as it does in traditional therapy – and depends on factors such as significance of motor impairment, degree of regulation, amount of practice outside of intervention, skill of the communication partner, and the client's familiarity and relationship with the communication partner.

This was not my assumption for the first 19 years of my career as an SLP, professor, and educator. Language-based intervention was the backbone of my practice as an SLP specializing in autism until I started working with clients on the letterboards. Some of the first clients I worked with on the letterboards were long-term clients whom I had been using traditional methods with for years and years. I quickly found that as the motor skills developed and my clients could accurately and consistently point to the intended letters, their communication became increasingly sophisticated. They used rich vocabulary, grammatically complex sentences, made keen observations and demonstrated age appropriate or better comprehension skills. This was not what I expected given my traditional understanding of autism. My clients began to show me that the traditional thinking about autism–including my own–was wrong.

I spent my first year on the letterboards in constant shock as my clients spelled things that I had not imagined them capable of expressing. I kept asking them, "how do you know this?" and they kept responding with some variation of, "I am always listening." As my clients became fluent on the letterboards and keyboards, they explained that their motor skills impaired their ability to communicate, to play, to establish friendships, but that they were always listening, observing and absorbing information. They were self-aware and sensitive. I found they each had unique personalities, perspectives, and styles of communicating. They each had their own "voice." I saw these unique voices not only in my clients but also in the communications of other nonspeakers working with other practitioners or their parents around the world.

Communicating by pointing to or typing one letter at a time is slow. Even though the nonspeaking individuals begin to communicate, it does not change their diagnosis nor their sensory and motor differences. They are still autistic, still have trouble managing their bodies, and struggle to be regulated physically and emotionally. Carrying over skills to new communication partners is not easy and requires time to build a trusting relationship as working with a new communication partner can be challenging and dysregulating. Communication is only as strong as the weakest partner, so each new person who is going to work with the client needs to learn how to use the letterboards, how to coach the motor, and to develop their skill set as a communication partner.

The field of autism is still young and we have much to learn. In fact, the first autistic that Leo Kanner studied, Donald Tripplet, is still alive (Donvan & Zucker, 2010). He has lived a life that Kanner would likely have never predicted. Although he was institutionalized as a preschooler, his parents brought him home after a year. He attended mainstream high school, graduated from college and lives on his own in his family Mississippi home. He has been embraced and accepted by his hometown community.

Certainly, more research is needed to better understand how to support nonspeaking autistics find effective ways to communicate. New multidisciplinary research is supporting the motor and sensory differences in autism (e.g., Fournier 2010; Focaroli et al., 2016; Robledo et al., 2012; Torres & Donnellan, 2015) and researchers are beginning to study forms of spelling to communicate as one method that some nonspeaking autistics have found helpful–an effort I enthusiastically support and participate in. Evidenced-based practice (EBP) is important and informs our work as speech-language pathologists.

ASHA's guidance (http://www.asha.org/Research/EBP) on EBP states, "The goal of EBP is the integration of: (a) clinical expertise/expert opinion, (b) external scientific evidence, and (c) client/patient/caregiver perspectives to provide high-quality services reflecting the interests, values, needs, and choices of the individuals we serve." As practitioners, we can contribute to the research enterprise by taking clinical data, analyzing results, and using that data to inform our daily practice. In my practice we have transcripts of every session with our nonspeaking clients as well as periodic video data. We can partner with scientists to develop ways to document and understand the clinical phenomena that we observe. Most importantly, we need the perspective of the speaking and nonspeaking autistic self-advocates who are the true subject matter experts; we can learn from their lived experience of autism.

Once you see a nonspeaking student spell out their thoughts, you can't unsee it. You have two choices, believe or do not believe what you are seeing. Choosing to believe means that there is more to learn about autism and that we don't yet have all the answers. Choosing to believe means you must change the way you practice and interact with your nonspeaking clients. My clients' ability to communicate via spelling pushed me into a complete paradigm shift, into the motor literature and research, and into advocating for the communication rights of nonspeaking individuals.

I have always been proud to be a member of ASHA. As a rigorously trained and experienced SLP, ASHA should allow me to use clinical experience and judgement to make the best clinical decisions to support my clients. Although there have not been any clinical efficacy studies on spelling or typing as a form of communication, you can see that there is strong research supporting approaches with motor based teaching I strongly urge you to withdraw the proposed position statements on RPM and FC and issue a statement of apology for the damage that has been done via the social media campaign around this proposal.

Respectfully submitted,

Elizabeth Vosseller, MA, CCC-SLP
Speech Language Pathologist
Owner/Director Growing Kids Therapy Center

References

American Speech-Language-Hearing Association.(2015 Sep). Apraxia a Common Occurrence in Autism, Study Finds. *The ASHA Leader.* 20(18). doi:10.1044/leader.RIB1.20092015.18.

American Speech-Language-Hearing Association. (2007). Apraxia of Speech in adults.*Information for the Public.* Retrieved on September 15, 2017 from http://www.asha.org/public/speech/disorders/ApraxiaAdults.

American Speech-Language-Hearing Association. (2007). Childhood apraxia of speech. *Position Statement.* Retrieved on September 15, 2017 fromhttp://www.asha.org/policy.

Biklen, D., Burke, J. (2006). Presuming Competence. *Equity and Excellence in Education.* 39. 166-175. doi: 10.1080.10665680500540376.

Courchesne, V., Meileur, A. S., Poulin-Lord, M., Dawson, M., Soulieres, I. (2015). Autistic children at risk of being underestimated: school-based pilot study of a strength-informed assessment. *Molecular Autism.* 6(1). 1-10. doi: 10.1186/S13229-015-0006-3

Donnellan, A.M., Hill, D.A., Leary, M.R. (2013 Jan). Rethinking autism implications of sensory and movement differences for understanding and support. *Frontiers in Integrative Neuroscience.* 28. doi: 10.3389/fnint.2012.00124.

Donnellan, A.M., Leary M.R. (1993). *Movement Disturbance. A Clue to Hidden Competencies in Persons Diagnosed with Autism and Other Developmental Disabilities.*Madison, WI. DRI Press.

Donnellan, A.M., Leary, M.R. (1995). *Movement Differences and Diversity in Autism/Mental Retardation*. Madison, WI. DRI Press.

Donvan, J., Zucker, C. (2010 Oct). Autism's first child. *The Atlantic.* (online). Retrieved on September 30, 2017https://www.theatlantic.com/magazine/archive/2010/10/autisms-first-child/308227/.

Edelson, M. (2016 Jan). Are the majority of children with Autism mentally retarded? A systematic evaluation of the data. *Focus on Autism and Other Developmental Disabilities.*21(2). 66-83. https://doi.org/10.1177/10883576060210020301.

Focaroli, V., Taffoni, F., Parsons, S.M., Keller, F., and Iverson, J.M. (2016 13 May) Performance of Motor Sequences in Children at Heightened vs. Low Risk for ASD: A Longitudinal Study from 18 to 36 Months of Age. *Front. Psychol.* 7.:724 doi: 10.3389/fpsyg.2016.00724.

Fournier, K. A., Hass, C. J., Naik, S. K., Lodha, N., and Cauraugh, J. H. (2010). Motor coordination in autism spectrum disorders: a synthesis and meta-analysis. *J. Autism Dev. Disord.* 40, 1227–1240. Doi: 10.1007/s10803-010-0981-3.

Jorgensen, C. (2005). The least dangerous assumption. A challenge to create a new paradigm. *Disability Solutions.* 6(3). 4-15.

Jorgensen, C. (2007). Presumed competence reflected in the educational programs of students with IDD before and after the Beyond Access professional development intervention. *Journal of Intellectual & Developmental Disability.* 32(4). 248-262. doi: 10.1080/13668250701704238

Jorgensen, C. (2016 Aug). *Inclusion is More Than Just Being "In": A Planning Process for Full Participation and Learning*; *Instructional Adaptations and Technology Tools that Support Inclusive Learning.* Presented at "Communication is More Than Just Speech. Building Inclusion Through Typing." ICI Summer Institute. Columbia, Maryland.

Landa, R.J., Libertus, K., Sheperd, K.A., Ross, S.W. (2014 Dec). Limited fine motor and grasping skills in 6-month old infants at high risk for autism. *Child Development.* 85(6). 2218-2231. doi: 10.1111/cdev.12262.

Leary, M.R., Hill, D. (1996). Moving on: autism and movement disturbance. *Ment. Retard.* 34. 39-53.

Robledo, J., Donnellan, A.M., Strandt-Conroy, K. (2012 Nov). An exploration of sensory and movement differences from the perspective of individuals with autism. *Frontiers in Integrative Neuroscience.* 16. doi: 10.3389/fnint.2012.00107.

Tierney, C., Mayes, S., Lohs, S., Black, A., Gisin, E., Veglia, M. (2015 Oct). How valid is the checklist for Autism Spectrum Disorder when a child has Apraxia of speech? *J Dev Behav Pediatr Journal of Developmental Behavior Pediatrics.:* 36(8). 569-74. doi: 10.1097/DBP.0000000000000189.

Torres, E.B., Donnellan, A.M. (2015) Editorial for research topic "Autism: the movement perspective." *Front. Integr. Neurosci.* 9(12). doi: 10.3389/fnint.2015.00012

June 12, 2018

Laura Nadine

http://www.lauranadine.net/?p=3556

Dear Board of Directors,

I am responding to the ASHA committee's conclusions on FC, RPM and other typing forms of alternative communication.

I am Autistic. I am also a music teacher, celebrating 25 years teaching this year, and a parent of an Autistic teen. My non-speaking students learn to play violin, viola, and cello from me acquiring the lifelong skill of playing independently on the instrument. This is not just as a fun therapy; my students actually learn music and learn to play their instruments.

While I was at Agnes Scott College as a Psychology major, I became involved as an Autistic Advocate, voicing my thoughts for the benefit of others. Fifteen years later, we have significantly more evidence to support theories on how the brain works than we did when I started on this path. However, I feel as though I am still having the same discussions over presuming competence, despite the emerging research supporting the idea that those of us with Autism are capable of significantly more.

I encourage you to take a moment to read the emergent truths that research has brought to us because autistic people like me choose to participate in this research for the betterment of Autistic lives. As a violinist, I would much rather spend my time playing my violin, but I choose to participate in research and be a voice because, until very recently, people like me were locked in hospitals. RPM and spelling-to-communicate are advances in thinking brought to us to help free Autistic people from the confines of their inner selves and express not just our physiological needs, but our hopes, dreams, and desires to be a part of a loving world. This is not abuse, it is freeing us from abuse.

If you think we are using these kids as our personal mouthpieces, then you give us way too much credit. In order to create the proposed illusion, a parent, as a speech partner, must create an entire being different from themselves, create different vocabulary, and continue this effort with amazing consistency. I love and appreciate the parents I work with, but none of them are so clever and devious as to pull of a hoax of this magnitude for this long with this level of consistency. In fact, there is more than enough evidence to support the amazing evolution a parent would have to go through to be multiple people and not be recognized immediately by the professionals they encounter on a regular basis.

As a professional or teacher, I would have to maintain not one illusion, but hundreds of illusions with precision. To spend my professional time and creativity developing a hoax or illusion of this magnitude would be a waste of my time. As a professional, I have spent hundreds of hours sharpening my skill as a violinist, a performer, and a music educator. Expanding my teaching base to include students with disabilities, especially those who cannot communicate by traditional oral means, adds a significant workload on me as a teacher. I have had to restructure pedagogy, create new approaches, research multiple communication modalities, and create a balanced physical space to welcome these students in. I gladly take on this responsibility to make music accessible to all students who wish to learn, consistent with my Suzuki Method training of "every child can learn." All students, no matter their diagnosis, pay the same rate per hour, eliminating financial gain. My motivation is strictly to share the love of music, and I do so successfully even with non-speaking students.

To that extent, as a professional, I would like to note that musical talent occurs at the same rate in my non-speaking Autistic students as with my neurotypical students. Some non-speaking students play with more accuracy than others but they all do so independently, and not because of savant syndrome. Given the hierarchical structure of the brain in regards to musical thinking, it seems to me that a cognitive delay so profound that these students are not able to independently speak using a method such as RPM, then it would stand to reason that they would also be unable to acquire the bilateral, complex skill of playing music on a violin independently. I would be quite the magician if I were inadvertently channeling my musical talent through them.

More importantly, why would I put energy into creating the hoax? We as advocates subject ourselves to constant scrutiny. We expose our deepest and most personal thoughts because we love the world we live in and want to be part of that world. I am Autistic and I have my own voice. I am officially diagnosed and received disability accommodations at Agnes Scott College. I was open about my diagnosis and voiced how it felt to have my sensory system on guard all of the time in very public ways so as to educate my fellow college classmates. I struggle with spoken language and have yet to successfully learn to speak a foreign language despite being raised around one. I was open to my classmates about how language was an issue for me, not in forming words with my mouth but in communicating effectively. To this day, I experience loss of speech when overly stressed, overly stimulated, or tired. Being open about this in a public forum opens me up to scrutiny. To get up everyday, go to school, and subject myself to constant trial and error was my choice. This was so because I was the first openly autistic student at ASC and I felt I could play a part in supporting other Autistic people that want to be better than subminimum wages, housing projects, and juvenile activity groups. In the spirit of eliminating financial gain, it is worth it to mention here that I personally still carry a $20,000 debt from college I cannot seem to payoff. Being open has not given me a nation of unsuspecting minds to rule or money filled pockets. But it has given the next generation a foot in the door.

My fellow Autistic people who use a letterboard subject themselves to this same energy depletion and scrutiny because they are the first. Being open, being the first means we take some pretty big sacrifices beyond the scrutiny and judgement that impact our daily lives and rights as humans. Why would we subject ourselves to all of this? Because the real cruelty is returning to the days when potential was not recognized.

RPM and other systems like it are the conduits that bring the inner intellect to the ears of a mostly verbal world. Similar to sign language for the deaf, the system requires knowledge of how it works and an interpreter for those on the outside. If I were, as a dancer, to learn a dance number and suddenly invite another person to dance with me, the steps would be clumsy and the chemistry off. As people with Autism, our communication partners, our educators, and our therapists must be able to dance with us. We must be able to trust them and see that they presume our competence, cherish our personalities, and avoid shoving us into the pigeon hole of normality. To remove access to this method simply because you do not know how to dance would be as cruel as cutting out the tongue of anyone who sings because we dislike the music.

More research is needed, and on this point we agree. Researcher Dr Vyacheslav Ryabov, in a study published in the journal Mathematics and Physics, found that dolphins can communicate using their own language. These types of discoveries are made because we wish to understand more about dolphins and how nature can help us develop further as humans. I would encourage anyone who wishes to understand the human mind to an even broader depth than we currently know to research non-speaking students and their preferred methods of communication. This issue with RPM and the like should be embraced as an amazing moment of wonder, open minded collaboration, and the next step in the human's need to be understood.

Thank you for considering my opinion.

Laura Nadine

June 21, 2018

Ryan M.
Ian N.
Tom P.

Re: [TIME SENSITIVE] ASHA Policy Statement on RPM

My name is Thomas Pruyn and I am a nonspeaking autistic who uses spelling to communicate.

I am Ryan McMahon and I am a nonspeaking autistic who uses spelling to communicate.

Like many other nonspeaking autistics, I, Ian Nordling, have found my voice by spelling on a letterboard to communicate.

Tom: We are a group of young adults who have undergone various tests, interventions, techniques and methods all trying to fix something that was purportedly broken.

Ian: The many other therapies fall short as they do not necessarily meet the basic need for meaningful communication. Do not limit my expression to a handful of pictures or icons. I have so much more to share.

Ryan: When one experiences apraxia, which is the difficulty connecting brain and body and executing purposeful motor, and is given tests using or requiring fine motor skills to measure intellectual ability he will undoubtedly fail. How valid can the results be?

Tom: My life is different because my body is wired differently than yours. However, my brain is bright. I have emotions and a thirst for knowledge, relationships, and to lead a life that is fulfilling.

Ian: Our story is not unique to us. We are a group of friends but more pertinent to the proposal, we are nonspeaking people who need a letterboard to communicate.

Tom: Being able to express ourselves reliably requires a letterboard and a trained communication and regulation partner.

Ryan: We deserve to have a voice. Stopping proper research through an attempt to discredit methods that use letterboards means people like me must speak louder than ever.

Tom: We write to you to implore you to consider the extremely negative impact of this proposal. Using the letterboard has allowed me to show my intelligence, to participate in the activities that guys my age enjoy like family game nights and intellectual conversations, and more importantly, to share my needs, wants, and dreams.

Ian: Like most people, I just need the basics to live. I need communication to live a life of autonomy. It is as important as food and water.

Ryan: It is most important to realize that this proposal promotes exclusion.

Tom: We ask you to reject the proposal and stand by those with motor, sensory, and communication differences. Include us. Accept us. Hear us.

Sincerely,

Ian Nordling, Thomas, and Ryan McMahon

June 25, 2018

Pablo Hernandez

https://nottootrapped.wordpress.com/2018/06/26/letter-to-asha/

Dear Ad Hoc Committee:

My name is Pablo. Can you imagine my life from a little baby? My having autism has been first good, when I am learning, but also hard because my mouth sometimes cannot say what my brain thinks.

Both IDEA and the Handicapped Act give me the right to learn in school, but they can't see what I might be thinking.

I have other hopes in this. Can I live with someone who maybe holds the letterboard? The main, not so manageable problem is that my hand has, back in the day, had a mind of its own.

So many, not feeling, think I lack intelligence. I gather my strength together to point to the letters, not losing my train of thought. For me it takes all of my concentration. Not always I can do it.

Something tells me that you maybe really might change your mind if you met me.

Pablo

June 24, 2018

[REDACTED]

I am writing to you today as the parent of a non-speaking 18 year old individual. The purpose of my letter is to urge you to withdraw your draft ASHA Position Statement on Rapid Prompting Method dated May 24, 2018. This Statement has the potential to cause (and may have already caused) people who spell, type or write to communicate to lose access to their preferred and most effective means of communication. This Statement is in direct opposition to AHSA's vision of "Making effective communication, a human right, accessible and achievable for all."

My daughter (who I will refer to as "AN") was diagnosed with autism and apraxia as a young child. As her mother, I made a vow that I would leave no stone unturned in an effort to help her achieve the greatest possible quality of life. I began by following every recommendation I received from the various professionals who became involved in our family's life, including speech therapists, occupational therapists, physical therapists, special educators, behavior analysts, psychologists and therapeutic staff support. AN received services at home (starting at age 1) as well as at school throughout her elementary and middle school years. At the age of four, she was placed in an intensive educational, behavioral and therapeutic program due to a lack of progress in her development, particularly receptive and expressive language. She remained in that program until the age of nine, when she transferred to another specialized, behavior-based school setting recommended by our local school district.

After thirteen years of speech therapy with several different speech language pathologists (SLPs) in various settings, AN still lacked any functional communication at the age of fourteen. She had been taught by certified SLPs using most of the tools and techniques promoted by ASHA, including picture communication boards, sign language, and speech generating devices. Her school practiced ABA-based Verbal Behavior in an attempt to integrate communication goals into all parts of AN’s day at school. Not one of those tools or techniques succeeded in helping AN develop any meaningful communication.

As you might imagine, entering adolescence without any way to express herself, AN’s aggressive and self-injurious behaviors escalated and she continued to make little to no progress on any of her goals, speech-language related or other functional skills. It was at that point that I decided to venture into alternatives to the standard therapies and educational approaches that were being offered. I figured we had nothing to lose, because at that point all the recommended, “evidence-based” therapies and interventions had failed my child.

The alternative I decided to pursue was RPM. To be honest, at first I was incredulous to think that my daughter could understand the information being presented to her in her first RPM sessions. I had been conditioned to believe that she was still struggling to understand even basic language or to identify and know the function and sounds of letters, much less be able to spell words. However, I was willing to give it a chance because all else had failed up to that point. It was suggested by the RPM provider that we treat AN’s disability as a lack of motor skill rather than a lack of cognitive skill. After a few days, we returned home and began practicing what we had been taught.

Fast forward almost four years to today. AN is able to type her wants, needs, hopes, dreams, likes, dislikes, political opinions, scientific fact, original poems and anything else on her mind without prompting or physical support. She does still require a communication partner to help her regulate her body and keep focus on what she is spelling or typing, but there is absolutely no translation or interpretation to be made. AN’s typed communications are undeniably and indisputably her own. Ask anyone who has met her.

AN’s breakthrough in communication has enabled her to fully participate in her own life and make decisions for herself. Her behavioral outbursts have diminished to almost non-existence, and when they do occur, she is able to communicate what is the problem and regain self-control within a very short period of time (less than a minute). She was able to successfully transition from the most restrictive educational environment (full-time placement in a segregated, specialized school) to the least restrictive (included with typical peers in regular education classes). She is enrolled in the local community college. She participates in doctor appointments and makes decisions regarding her care. She expresses about her concerns about the environment and about civil rights. She shares her plans for her future. She participates in family life and develops deep and meaningful relationships with her loved ones because they are able to get to know her inner thoughts.

Without having had access to RPM and open-minded professionals, AN would in all likelihood still be injuring herself in frustration. Her progress over the last four years can only be attributed to the paradigm shift that occurred when we began teaching AN motor skills to point to letters on a letter board (and later a keyboard) and engaging her mind with age-appropriate lessons on a wide variety of topics. Only after the previous “evidence-based” approaches were abandoned and the alternative, unproven approach was incorporated did AN develop the ability to use language to express herself.

Adoption of ASHA's draft position statement would serve to do the opposite of what it claims. It would *deny* non-speaking or minimally speaking people the communication rights of autonomy and freedom of expression. Rather than attempting to shut down the use of a method that has thousands of families providing anecdotal evidence of dramatic, life-changing success for their non-speaking loved ones, ASHA should be attempting to learn from those families' experiences. ASHA should be listening to the non-speakers who have reached their goal of independent typing about their experiences, regardless of the method they used to achieve that goal. ASHA should be working to scientifically validate the principles of RPM and other non-traditional methods so that your organization's vision of "making effective communication, a human right, accessible and achievable for all" can be fulfilled.

June 11, 2018

Philip Reyes

philipautism@yahoo.com

Hello ASHA,

My name is Philip Reyes. I am an RPM user. I am writing you to reconsider your position on RPM. I cannot communicate my ideas without someone to help me in various ways. I need help to start, stay on track, get through impulsive loops, and calm me so I can spell my thoughts on a letterboard or keyboard. I am asking you to put yourself in my shoes. I would be trapped in my own mind if not given RPM. I have tried many other methods to learn to communicate: ABA, speech, OT, Alt-Chat, and PECS. I was not able to make more than a few simple requests using those methods. I wanted to say much more. I was frustrated most of the time. I could not do much in school. I was made to do very basic lessons over and over without hope I would advance. I never want to return to those methods because they did not work for me. I could not express my true thoughts and feelings with them.

I fear that passing this proposal will take away the support I have at school. I have made so much progress at school. I started at regular public school in grade five. I am happy with how far I have come. When I started, I had lots of meltdowns and anxiety. I had poor self-regulation. I was not good at communicating. I started in all special education classes except specials. I slowly got better at spelling with everyone and regulating my body. I got to add more regular classes with my neurotypical peers. I got to have more normal experiences. I even walked across the stage for 8th grade graduation and got to go to the dance. I am now finishing my Freshman year in high school. I have two amazing aides who support me so I can participate in regular classes and take the tests. I have teachers who believe in me and cheer for me. I have gotten better at sitting calmly and controlling my body. I even gave a presentation in front of my global studies class. I love school so much.

I fear the proposal will prohibit educators from working with me unless I can type completely independently. This may take me a very long time. I cannot waste my life while trying to become perfectly independent.

I urge ASHA members to do what is humane and good. Think of me and the many others who can be given a voice and a better life because of RPM.

Yours truly,

Philips

July 12, 2018

Lindsay Melda

lindsaymelda@icloud.com

I am a parent of a child with Autism, who has very limited verbal language. When my son, Adam, was diagnosed with Autism at the age of 2 he had no spoken words and was severely frustrated. This was especially difficult to see as a parent because Adam had spoken language and lost it over a period of a few months. We spent years trying traditional speech therapy, ABA therapy, OT, and Floor time therapy. All of this work encouraged Adam to use his spoken language and he was able to gain around 100 spoken words to meet his wants and needs. We tried sign language and picture card exchanges for years with absolutely no success.

Our lives changed when Adam turned 6 and we learned of a new therapy called RPM. All of our therapist had always believed Adam had more understanding of language than he was able to "prove" based on evidence they had seen while working with Adam. RPM finally allowed Adam to be able to "prove" that he did have the receptive language skills we all thought to be true. Adam has a very hard time with body control and motor planning and the prompting in RPM is absolutely neLike all skills we teach through prompting (riding a bike, swimming, toilet training, dressing skills, etc.) our ultimate goal is to fade the prompts. It's important to point out that we would have never given up on teaching any of these skills because of a fear of becoming prompt dependent. cessary to allow him to communicate. At this point in our process, auditory prompts are especially important. It's similar to how a coach would remind a baseball player to keep his eye on the ball. Adam needs auditory prompts to keep him focused on using his letter board. Without access to his letter board with a communication partner to help keep him on task, Adam would have no way for effective communication.

While learning to communicate by using a letter board has been a positive life changing event for not just my son, but my entire family, it has been filled with frustration. I constantly have to fight for his right to choose his preferred method of communication. I spend endless hours educating the community around us to understand that not speaking does not mean not understanding. I find encouragement knowing that throughout history many other individuals who chose to communicate differently, like Helen Keller and Stephen Hawkins, were able to change the stereotypes people believed. I find hope in new tv shows (like speechless) which brings this issue to popular culture and by the many individuals (like Carly Fleischmann) proving that nonverbal individuals can communicate.

I am very disappointed in the proposed policy by ASHA attempting to deny my son's communication choice. This type of policy would make communication less accessible for children like my son with motor planning challenges and limit his rights as a nonspeaking individual. I implore you to withdraw this proposed statement and issue a formal apology for the damage that this committee has already done.

Sincerely,

Lindsay Melda

June 12, 2018

From: Parent of Autistic

HPatton@dimensionssouth.com

To: American Speech-Language-Hearing Association (ASHA)
Attn: Board of Directors

Re: Proposed Position Statements on use of Facilitated Communication (FC) and Rapid Prompting Method (RPM)

Dear Board of Directors of ASHA,

I am the parent of an autistic 15 year old. I recently read the Proposed Position Statements on use of Facilitated Communication (FC) and Rapid Prompting Method (RPM). I am writing to express concern over the proposed positions.

My son was diagnosed as autistic just before he turned 3. He has used various therapies over the last 12 years that included: speech therapy (ST), occupational therapy (OT), applied behavior therapy (ABA), music therapy and social skills training. He is a talkative individual who is able to express some of his needs, but mainly uses scripts to communicate.

Just 3 years ago, my son was introduced to RPM. At first, he complained a great deal about using letter boards since he could speak. However, we continued with RPM because one of the primary purposes was to expose him to age level educational materials. In addition, RPM posed no harm or danger to his health or wellbeing unlike so many other "therapies" offered up to parents of autistics.

While I was not certain about using the letter boards in the beginning due to the prompts, I was able to witness the fade of the prompts and understand that the prompts were not any different than those used in ABA sessions and at school with assignments.

Since using RPM I have witnessed positive changes in my son. He is using more purposeful spoken words and scripting less. He has been able to spell that his mouth is a motor that is not always within his control - most often just the memorized scripts that fill his mind spill out of his mouth. Using a letter board forces his concentration and slows down his processing to enable more true, or as he now says “deeper”, thoughts to come out. He is able to have meaningful conversations on the telephone with relatives. Most impactful has been his statement that before he was able to use the letter boards, he was stuck with his spoken nonsense and thus held back from new things. You see he is anxious, always. His response to every new thing is “no”. Now that he has access to use a letter board, he has the opportunity to override his spoken nonsense and say what he might like to try.

I am not a scientist. I am a parent. I have been in this autism life with my son for 15 years. I affirmatively say that exposing kids to non-threatening, non-invasive communication methods and age appropriate materials has changed my son and our life. I firmly believe that his spoken words were the familiar, worn pathways in his brain and somehow the use of letter boards has created new pathways.

Given the above, the ASHA Proposed Position Statements on use of Facilitated Communication (FC) and Rapid Prompting Method (RPM) concerns me because it will impede further research. How can we have more evidence to support or discredit if ASHA finalizes this position statement? No SLP will be willing to learn or practice to become an expert able to give expertise or judgement. This is contradictory to the nonprofit mission of accessible communication for all. It is much harder to get a position reversed than to pass an inappropriate statement in the first place. Consider the impact this will have on not only research, but a good deal of the population ASHA is meant to serve. As a Board Member of ASHA, you have a fiduciary duty to support the mission of your organization and serve your community members. As such, it is imperative that you vote against the Proposed Position Statements on use of Facilitated Communication (FC) and Rapid Prompting Method (RPM).

As a Board Member serving a nonprofit, it should be extremely concerning that the committee put forth this proposal without allowing any evidence from actual users of RPM or FC, or even ASHA members that have direct experience with these methodologies. Again, a contradiction to the mission of ASHA. Lastly, to even consider any proposal of a committee comprised of people who have known bias against methodologies is an obstruction to the mission of the ASHA organization. Finalizing the Proposed Position Statements on use of Facilitated Communication (FC) and Rapid Prompting Method (RPM) is a hindrance to research, a contradiction to the ASHA mission, and a clear danger to future autistic parents like me who have children whose speech does not fully represent their abilities and for whom other methods have not helped.

Sincerely,

Concerned Parent

June 12, 2018

Amy Greiner

amy@abgraphicdesign.com

I am deeply saddened to hear of ASHA's attempts to discredit people like my son who use RPM. My son Joshua is 16. He have autism, is completely non-verbal, has severe motor planning difficulties and cortical vision impairment. Starting from the age of 13 months Josh has seen numerous SLPs, often two at one time between school and private. We have used PECs since the age of 3. He has used AAC since the age of 5. He still uses PECs and his AAC (currently using Dynavox Compass), however the most these methods have allowed him to communicate was the ability to make requests of food, videos, activities, etc. He has received ABA therapy since he was 3.5, some years for more than 35 hours/week. ABA was never effective for him. He would sit patiently but was never able to make progress in any of the variety of skills that were worked on.

When Josh was 13 years old we first tried Rapid Prompting Method (RPM) with a certified practitioner. The nearest location was in Denver which was a 14 hour drive for us. Since then, for just over 3 years, I have done RPM lessons with Josh for 30 minutes 1-2 times/day. We also see an RPM practitioner 3 times/year. Progress has been slow but for the first time in his life we are actually seeing progress. In the last 3 years he has gone from working on identifying the numbers 1-5 to doing math at a 7th grade level. He has gone from identifying his name to communicating the themes of books. He has always understood everything but he has not had a way to communicate this due to his severe motor planning difficulties, vision impairment, and impulsivity. He cannot control his body, similar to a person with Parkinson's, but inside, his mind is just like any 16 year old. RPM started by teaching him how to make choices, how to point, and eventually how to point to letters to spell. All lessons are age appropriate and engaging to capture his interest.

Recently, Josh has been able to tattle on his little brother and to tell me that his aide was using his phone on outings - both things I later found to be 100% true. After a recent OT session he was very upset in the car ride home. I thought he was upset because I forgot to bring snacks but when we got home he spelled out "The ladder makes me feel stupid". I was able to share this with his OT and they now do the ladder on another side of the gym away from the preschool class that it had been right next to.

In addition to the communication gains he has made big gains in other areas. When we started he could not sit still for me to read to him, even for a full minute. Initially I would follow him around the house while reading to him. Now he sits happily for up to 30 minutes while I read to him. We read age appropriate books as opposed to the baby books like "Green Eggs and Ham" that I thought he enjoyed prior to RPM. Recent books we have read include Animal Farm, 1984, Fahrenheit 951, The Giver. His favorite book so far is the Alchemist because "it is about a person on a personal journey." We also now play family games, go on more outings, and do art projects. Josh has been able to communicate to me that he enjoys these activities - in the past, when he would get upset I thought it was because he didn't enjoy them. Instead it was his anxiety that he couldn't control. This is improving.

RPM is not an easy fix. It takes a lot of practice - in our case daily practice. It isn't something that could likely be done one time/week with an SLP, at least not with someone with the level of challenges that my son has. We personally know people who have made much quicker progress and one/week may be effective in these cases. But the tenants of RPM - presuming competence, teaching how to make choices, teaching how to point, using age appropriate and engaging lessons - could be done with any child, and are not dissimilar or counterproductive to other types of interventions. I have heard concern that RPM requires too much prompting but we have done much much LESS prompting with RPM than was done with ABA or other interventions. Other than the first few months we haven't used any physical prompts at all and in fact true RPM insists on the use of no physical prompts at all. In the more advanced forms of RPM keyboard or letterboard use is completely independent. I respectfully ask you to meet with the young adults who have managed this level of communication - they are not hard to find. I would be happy to give you a list if you are interested - we personally know so many who would be happy to meet with or talk with you. There are even a growing group currently attending college, one is featured in an Apple commercial. This is such an important intervention. These kids work so hard, they deserve respect and support. Please give this the attention that these kids deserve. This rash action will hurt so many by denying them access to a form of education and communication that as human beings they are entitled to.

Respectfully, Amy Greiner

June 13, 2018

Tracy Gunn

dtgunn@mweb.co.za

Good day

I am responding to the peer review on Proposed ASHA Position Statement: Rapid Prompting Method (RPM) and Facilitated Communication (FC).

I am a Speech Language Pathologist working in South Africa. My clientele consists primarily of non-speaking and minimally speaking autistic children. I felt compelled to respond to your review proposal as decisions reached in the USA usually have ripple effects around the world, and I am horrified by the thought of the type of thinking reflected in this peer review proposal coming to my country.

As a profession, we have an obligation to uphold our clients' human rights by assisting them in their communication. In our vast field, there is definitely not one solution to all communication difficulties. Each person has a different profile of abilities and should be provided with communication that fits their needs and abilities. Speech Language Pathologists should have the right to choose the best form of communication to fit the individual.

It is beyond my comprehension that a body that is supposed to represent speech language pathologists would attempt to silence the voices of people who have fought so hard to find them. It goes against your motto and mission statement. There are a growing number of individuals who have found their voices through the types of communication you are trying to discredit. These are the voices that you should be listening to, not the voices of people trying to silence the clients. ASHA should also be listening to its own members who are using these methods, and not trying to discredit them.

ASHA should withdraw this peer review immediately. Furthermore, they should apologise to the therapists who are using these methods to work with and empower clients. Mostly, ASHA should apologise to the people whose voices are in danger of being silenced by your actions.

Kind regards

June 13, 2018

Deborah Flaschen
9 Commonwealth Avenue PH
Boston, MA 02116

deborah.flaschen@gmail.com

American Speech-Language-Hearing Association
Attn: Board of Directors
2200 Research Boulevard
Rockville, MD 20850-3289

Dear ASHA Board of Directors:

My name is Deborah Flaschen. I am the parent of a 27 year old autistic adult. My son is partially verbal and can type independently.

We discovered Facilitated Communication 4 years ago. It has changes my son’s life and that of his family as well. His previous verbal and typed expressions were all very concrete: concrete words describing concrete events or things. His facilitated typing is very different. He loves to talk about abstract thoughts and feelings while typing with a facilitator. He is able to type with several facilitators and his unusual syntactic style and philosophic perspective is consistent across all of them.

I am reluctant to provide you with examples of his typing because I fear that you will be close minded and create a reason to discount my son’s words. That would be infuriating as well as painful.

I know you are committed to evidenced-based practices. Rather than eliminate CHOICE, you should be investing in creative ways to asses the effectiveness of facilitated communication.

Please do not take action that will limit the choice of individuals without a voice. I know how much facilitated communication has changed the life of my son, his family and his community. Whatever ASHA does or doesn't do won't change our lives, BUT it will harm many other families who are not independently in the position to explore all options to provide access to their son or daughter's voice.

Sincerely,

Deborah Flaschen

June 14, 2018

Laureen M Forman

lforman@lforman.com

I am the parent of a non-speaking individual who also has a movement disorder. He has come very far because of intense OT, PT, Speech, ABA, RDI, MNRI, Anat Baniel Method, Cranial Sacral, Acupuncture, Hippotherapy, Swimming, Surfing, and many more interventions. We stopped formal Speech as a therapy when he was 5 because of the way they were using his DynaVox.

He started using a DynaVox at age 4 but before he could get one from school, he had to prove competency using PECs. To me, PECs isn't a communication system that grows with a person – can you see a 15 year old using a PECs system in high school? And what really bothered me is that he had to show competency, without being taught, before he could get access to communication.

We teach deaf children sign language.

We teach blind children braille.

Why is it wrong to teach a non-speaking person or limited verbal to spell and use a keyboard?

My son started to use the DynaVox and we were ecstatic. However, I realized something during this time too, it was only being used as a requesting device. Everything that was taught to him was "I want" and he had to press that button before anything. It never grew much from there. That is limiting. No child walks around requesting all day.

The other default for non-speaking kids is to interrogate them – all day (i.e. yes/no questions only). Would you like to be interrogated every day at work and all day at that? I don't like to be interrogated because it's stressful and used by the Police to get to the bottom of a crime.

The crime our kids have committed is they do not use verbal communication. However, they have thoughts and feelings too, they also want to participate in conversations. They don't want to be questioned all day long.

I want my children to be literate - to be able to speak or write and get their thoughts across and also to have meaningful conversations. This doesn't happen with the way these devices are being used – specifically at schools where all socialization takes place.

When my son had been given the opportunity to spell, on a keyboard, it was magic and I will remember his first words – I love that. It was eye opening. He was fully supported at his school with this method and he was showing how much he really knows. Unfortunately in 2017, the SLP at school decided that using a keyboard wasn't appropriate because of the beliefs that a person who has motor challenges and my need someone to be near them to keep the person focused wasn't real so he was denied access and support. That resulted in serious Self-Injurious Behaviors – and he doesn't do SIBs regularly and rarely in our home environment where he is fully supported and included – which showed that he was frustrated and angry being denied communication.

This is blatant discrimination at it's highest form – that an organization, such as ASHA is promoting communication for all – will not support people who happen to spell one letter a time to communicate because they have motor planning challenges? That's okay to you?

You are promoting and encouraging a way for everyone to then marginalize these kids who will become adults that's it's okay to not give access to communication because they do not conform to your standard. What you are really supporting is that only certain people are allowed to form human connections through communication. To me, that is the biggest travesty.

I am encouraging you to withdraw these proposed statements, which are discriminatory, dehumanizing, and destructive to our kids, and adults who do not have verbal communication. Need I remind you that 80% of communication is non-verbal, need I remind you that behavior is communication, and need I remind you that your own mission is communication is a human right. You statements clearly violate this and are disenfranchising a whole group of people – and for what reason? They cannot speak and get loud so it's okay? Well, they are speaking and will continue to speak. This community is growing and will continue to grow. The question remains, will you decide to really show that Communication is a Basic Human Right.

I am also asking for a formal apology for your destructive statements that discriminates against a class of people.

My family's motto is "Do what works to help our son live a life a purpose". If we follow your guidelines, then the purpose goes away. Is that your purpose – to take away others meaningful lives, human connection and purpose? If so, I will be sure that everyone knows that I cannot support or listen to ANY ORGANIZATION THAT IS PROMOTING DEHUMANIZATION OF PEOPLE. You should be ashamed at your statements.

What if you woke up tomorrow with aphasia, couldn't move your arms, and had no way of communication – and no one helped you communicate because you couldn't even get to the right letter on the keyboard to communicate and your family all said, well, you can't point to the letters without assistance so you cannot communicate anymore. How would you feel?

Sincerely,

Laureen M Forman

lforman@lforman.com

June 14, 2018

Linda Tino

linda.tino13@gmail.com

To whom it may concern,

This letter is in response to the ASHA proposal to reject letterboard use for children with disabilities. I, as well as my entire family, are deeply concerned over this decision. Here is why….

We have a 25 year old son who has autism. For 24 years of his life, my son was able to communicate verbally like a toddler. He could express basic wants and needs but that was about it. When asked what he had for lunch for example, he could not always reliably tell you. Not being able to express himself led to many episodes of frustration and aggression over the years. That all changed a little over a year ago.

We had our son participate in a Spelling to Communicate workshop and had wonderful results. We learned from that experience that our son, although seeming like he wasn't paying attention, was listening to everything and retaining and understanding what he was hearing. The child that we thought had the intelligence of a toddler was as intelligent as someone his actual age and even beyond. Since then he has been going to S2C sessions twice a week as well as working on it at home with me (his mother). I don't know how someone could sit in and observe a session and actually come to the conclusion that my son's responses were NOT from him. As a matter of fact we have had many observers…..friends of ours who are physicians, therapists, other parents of autistic children, family members etc…and they all come away being amazed and believing in it fully. Yes, in the beginning there is some verbal prompting "keep going", "go to it" but NEVER any hand over hand in our method. Over time the prompting fades. My son is now able to express himself fully and completely while the communication partner simply holds the board in front of him. Many times they can be completely silent, and still my son has coherent and thoughtful things to express. He has talked about various events that have happened in the past that the communication partner would not have known about. He has also named people that the CP also does not know. How could that happen if the CP is influencing his communication? When I am doing the letterboard with my son, many times I think I know where he might be going with something, yet he always surprises me by wording his thoughts his own way and not the way I was expecting.

S2C has completely and utterly changed the trajectory of my son's life as well as that of our entire family. Yes, we still have the usual autism struggles but now we can ASK him why he is upset instead of guessing so we can help him. Now he can TELL us what is the matter if we suspect he is not feeling well. He has expressed what goals he has for the rest of his life. He is happier and more interactive and we have changed our way of thinking about him, and include him in things that we previously wouldn't have. I also see it improving his verbal skills. He loves to read aloud to us what he has just spelled and always with a smile.

You tell me what autistic person would sit in sessions for hour after hour, week after week for the past year if someone ELSE was doing the speaking for them and they were getting nothing out of it? It just wouldn't happen. He happily goes to each session and asks when the next social group session is!

Several months ago my son told us that he thought his entire education was a waste. He was taught well below his age when he was capable of so much more. Through no fault of our own or the wonderful teachers he has had, we did not know how intelligent he was and how much he understood. Now we know, and this method can help younger autistic children in schools today. I wish we would have had access to it when my son was in school.

My hope is that ASHA will withdraw the proposed statements about letterboard use and issue a formal apology for the damage that has already been done. The civil rights of individuals with disabilities need to be upheld and they should have a choice of and access to their desired communication method.

Please do the right thing for our kids.

Sincerely,

Linda Tino
linda.tino13@gmail.com

June 15, 2018

Michelle Lubetsky

mc.lubetsky@gmail.com

I am an educational consultant affiliated with a public education entity. In my role, I assist teams in their efforts to help students to access instruction within their school setting. I am trained as a Behavior Analyst and I utilize these strategies frequently to systematize instruction and monitor progress. However, even with the most comprehensive behavioral plan, implemented with fidelity, some students do not respond to the hierarchical, mastery-oriented approach of applied behavior analysis.

It has been my great privilege to know such a group of students, both during their “ABA days”, and again after they learned to control their bodies and to spell via pointing to letters on a static board. These young people, who were once known as “behavior kids”, finally learned a strategy to allow them to actively and successfully participate in age-respectful learning and discourse!

I witnessed a young man explain to his physician how medication affects him. This is a critical, health-related right! I witnessed this young mans’ teachers honor his innate intelligence that previously lay undetected beneath the surface of a body that betrayed him. I witnessed an adolescent seek out friends by asking to join their story-writing lesson. And I witnessed administrators welcome and embrace the inclusion of students who are non-speaking or minimally speaking to take part in the whole school experience. Each of these students spells without physical cues. Verbal prompts are available to get started and to keep going, mirroring the types of prompts afforded to any student, using any type of aided speech strategy.

I am literally shocked, that a group of people would disseminate blanked statements to discredit and silence the voices of vulnerable individuals who have waited their whole lives to be heard. It is their civil right to express themselves; it is our duty to listen! It is unethical for this Ad Hoc Committee to produce such damaging rhetoric without ever experiencing the methodologies first hand.

To the Committee: Please meet with folks who spell, whether they use an alphabet board, keyboard, or digital device. Open your eyes and your ears to the authentic messages of a courageous, expressive group of individuals! Learn about their interests and engage them in chats about science, sports, the arts, or pop culture. You will be amazed and enlightened and you will honor them as individuals who have something to say! Allow the values of personal dignity and respect to propel you to withdraw the proposed statements and thereby, permit our students and our loved ones to access their basic fundamental rights.

Best regards for a welcoming, inclusive future,

Michelle

June 17, 2018

Niko Boskovic

loretaboskovic@gmail.com

My name is Niko Boskovic, and I have used a letterboard to communicate for the past four years. I use it in school, for homework, at work, and pretty much everywhere I need to make my thoughts and desires known. I have about a dozen people with whom I letterboard. They've been trained to work with me for a reason that is obvious: to be my voice. If I relied on the words that SLP's taught me, nothing would be understood because my verbal communication is so affected. Maybe I would have learned to communicate with another modality, but letterboarding was so natural and fit so well with my abilities that I took to it like a fish to water.

Hardly a day goes by that I don't thank my luck stars that I know how to letterboard. My life would be so different: I wouldn't be in general education; I wouldn't be on my way to graduating with a regular diploma; I wouldn't be working at Trader Joe's for $13 an hour. The only thing missing is having a girlfriend, and I guess that's normal for a 16 year old.

What I'm trying to say is that being able to communicate has changed the trajectory of my future. I am irate over the notion of a committee of non-experts is trying to take away this form of communication. It seems like a personal vendetta, to be honest. I can't understand what their motivation is except to stifle the voices of people with disabilities. This is where we are presently: the able-bodied deciding what's best for us. I say enough to that historic oppression - your biases aren't fooling anyone.

- Niko Boskovic

June 17, 2018

Rita Rubin

rita.rubin943@gmail.com

There are so many instances of non-verbal or limited verbal people reliably using Facilitated Communication, it would be unfair to prevent additional people from benefiting from this method. The position statement does not mention the studies that prove valid communication. I agree that influence is possible with a poorly trained facilitator, but the way to deal with that is better training and validating communication in cases of abuse allegations. We must remember that not all allegations made by verbal people are valid either.

Why would the word "allegedly" appear in the definition? Also, the way it is written, it appears that the definition by Syracuse University includes the word "allegedly". ASHA should use the neutral definition appearing on Syracuse University's website http://soe.syr.edu/centers_institutes/institute_communication_inclusion/what_is_supported_typing/default.aspx

The literature review was biased.

SLPs certainly can inform parents, guardians, etc. of the controversy surrounding FC, but they have an ethical obligation to present parents, guardians, etc. with non-biased information. The decision whether to introduce FC to a child or a conserved adult should be left to the parent, guardian, teacher, etc.

This would be a disaster in the school system and in communities where FC is used in adult services. So many of our children with severe communication disorders are now doing grade level work and succeeding with the use of FC, it would be extremely detrimental to their education and lives outside of school.

I am the mother of Sue Rubin, an essentially non-verbal person with autism who has been using Facilitated Communication since 1991. For the first five years Sue required some level of physical support – in the beginning the facilitator pushed back on her hand, wrist, or arm forcing her to move that body part forward, with an out-stretched finger, in a purposeful way toward the target. This physical support slowly faded over the five years she was in high school where she was taking college prep courses. She felt that when she entered college, as long as a facilitator touched her anywhere on her body, people would question whether she was typing her own thoughts. She also knew she had to take the SAT. It took her 16 years to earn a Bachelor's degree. During all of those years in high school and then college, her teachers/professors did not doubt she was doing the work. They watched how she listened to the lecture, then reached for her communication device to independently type the answer. She also used idiosyncratic language across different facilitators. Sue uses Facilitated Communication in Supported Living, as the CEO of her consulting business, in the community and with friends. However, each time a new facilitator is hired, we have to begin again with some level of physical support now lasting for weeks, not years. I encourage ASHA to withdraw the proposed position statement.

June 18, 2018

Kari Nyland

kariandjohn@hotmail.com

Dear Board Members of the American Speech-Language-Hearing Association (ASHA):

I request that you **withdraw** proposed statements that would restrict the use of Facilitated Communication (FC) and Rapid Prompting Method (RPM) by speech-language professionals, parents and people with disabilities. I also request that you issue a formal apology for any damage that has been caused to the civil rights of non-speaking individuals with disabilities through the proposal of a statement which discredits FC and RPM as an effective form of communication.

I am an educator. I have taught since 1987. I have taught neurotypical children and adults in a variety of settings. For the past 17 years, I have been teaching my son, who has significant special needs and who is non-verbal. In teaching my son to communicate I have used behavioral methods. I have used picture exchange methods. I have used sign language. I have used social based programs. I have used a variety of communication devices. The only way that I have ever been able to effectively communicate with my son is through a letterboard. It took him two years to learn how to point at letters; however, currently he is spelling complete paragraphs. He is completing complex algebra problems. He is using a letterboard to tell us what he wants. This past weekend, when he became very agitated and I did not know why he was agitated, he spelled, "I GOT A BEE STING." I was then able to immediately offer first aid which is very important since he has been known to have severe allergic reactions to bee stings. His use of the letterboard may have saved his life.

As an educator, I know that every single child who enters my classroom is unique. Every single child invites me to consider a variety of strategies to help him or her. I am thankful that I can consider different types of strategies when I am figuring out the best approach for each child. As a professional educator it is critical that I have the opportunity and endorsement of a variety of strategies. FC and RPM are appropriate communicate strategies for some children and adults with disabilities. I believe it is up to the individual professional providers and parents to decide if FC and RPM are something they want to invite a person with communication challenges to consider. If you, as an organization, prevent professionals and parents from offering FC and RPM to people who may benefit from these communication opportunities you may be negatively affecting their quality of life because they may not have any other way to communicate. If I was not able to use a letterboard with my son, he would not be able to tell us he is in pain. Now, because he uses a letterboard, he can tell his doctor on a scale of 0 being no pain to 9 being lots of pain how much pain he is experiencing. This ability greatly enhances his quality of life.

Since some parents and educators, myself included, have found FC and RPM to be extremely helpful in communicating with their children and adults with disabilities, I trust that you will revise the proposed statement to promote further research to characterize the appropriate indications and techniques of these promising methods. Thank you for taking the time to read this letter.

Kari Nyland
Educator, Parent

June 18, 2018

Lorielle Moorhaus

lmoorhau@emich.edu

I was shocked to learn that your organization plans to formally state that they do not consider RPM a valid method of communication. I saw that this is because you do not consider RPM to be "evidence-based." As a disabilities scholar and a special educator, I do understand the importance of using evidence-based practices; however, RPM could not be MORE evidence-based. The evidence is everywhere, although it may not meet your scientific standards. Maybe your organization needs to do some formal research on RPM, so that we have more scientific data to examine. I think you would be surprised at your findings. Please be cautious before you make a statement that delegitimizes this powerful tool for people who do not speak to communicate.

June 18, 2018

Ludy Lukose

ludyjoe@gmail.com

Response to the ASHA Ad HOC Committee's proposal to "debunk" RPM as Pseudoscience:

Dear Members of ASHA board,

I am a board certified Physician and the mother of an Intelligent boy with Autism and severe verbal and sensorimotor disabilities. I am very concerned about the new proposal from ASHA Ad HOC Committee regarding Rapid Prompting Methodology of education for Autistic Individuals.

In this letter, I would like to provide a brief summary of the course of educational life my son had till date and my observations as a member of the scientific community.

At the very outset I would like to state that having practiced Medicine for 15 years, I value and incorporate evidence-based medicine in my practice. However, having lived for 40 years, 11 of which were spent intensively researching and practicing various educational modalities for my son with disabilities, I have reached the conclusion that no treatment modality can be "one size fit all", even if it is Evidence based.

"*Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups*." Scott Myers MD, Management of Children With Autism Spectrum Disorders, Pediatrics, 2007 http://pediatrics.aappublicati ons.org/cgi/reprint/120/5/11 62

I started out with the well known evidence based ABA methodology, for my 3 year old son, immediately after he was diagnosed. Even when I didn't see any significant benefit from the Discreet Trial Interventions [sold to me as ABA interventions by school personnel] I kept it going, 30 hours a week, and my son fighting it all the while. We kept up ABA based Speech Therapy and OT , both in school and privately . I watched as the therapist restrained my son because he was "flight risk" and rewarded him for some "desirable" behaviors . All this went on until my Neurodevelopmental Pediatrician was unable to answer why I didn't see much improvement even with every treatment that had all the evidence backing. I finally came to my senses that all of this was useless when another expert reported that if my son didn't improve by 6 years, not to expect much from him.

There are no guidelines to help the situation I found myself in. Discovering DIR/Floortime was probably the only saving grace to the guilt laden sleepless days. We finally found ourselves in my son's "world". Understanding what his "behaviors" meant and validating his emotions, we, slowly but surely, made progress, for the very first time. Now because DIR/ Floortime lacked so called evidence, we paid for the therapy out of pocket. Armed with Speech Therapists, Occupational Therapists and psychologists trained in DIR, we spent the next 3 years relentlessly trying to undo the harm I bestowed on him his first 3-4 years of therapy.

Then I was introduced by my OT to Rapid Prompting Method. Unlike the public school officials and teachers who told me I had a smart boy who always tested as intellectually handicapped on their standardized psychological evaluations, much to my frustration [little did I know that the experts didn't have the right tools to accurately assess him] and who were happy to have low expectations on his IEP; my OT advised me to presume competence in him.

Presuming competence was a novel concept and one that my analytical mind had a hard time coming to terms with. Soon I realized that it was similar to positive thinking, which has been backed by science in recent years. No harm can be done by assuming my child has used his ears, eyes, touch , vibratory, proprioceptive sensations to learn behaviors, concepts and skills that were not measurable because lack of appropriate testing measures. Why would I subject him to low expectations if I can't prove he lacks intelligence?

We have not looked back since the day I believed in my son. He started with letterboards and over the next 3 years, has started using keyboard to type. Granted he needs a facilitator, but even after being surrounded by teachers as facilitators in his private school, and myself after being trained, he has his own distinctive style of communicating. How can all of us exude the same effect in him?

Now he has an avid and relentless advocate on his side, his mother.

In the next few paragraphs, I will address all the issues raised in the ASHA Ad HOC committee report.

1. *According to HALO, RPM is a "brain-based" teaching and assistive method designed to establish and promote pointing-based textual communication in people* ***with intellectual*** *and developmental disabilities, usually autism.*

   Response: The very concept that autism is always associated with intellectual disability is debatable and with less than valid standardized tests for nonverbal kids, the authority experts express in this issue is questionable. Nowhere in HALO website is above statement [with intellectual disability]found, rather simply deduced by a biased investigator.

2. *The role of the "facilitator" in the construction of messages delivered by RPM is to control the communication board and to confirm any "messages" delivered. Therefore, it is not possible to rule out facilitator influence over messages delivered using RPM. Facilitator holds and moves the letterboard.*

Response: Though we don't exactly know the etiology of Autism, we know several kids with Autism have motor planning problems. They are not able to execute a simple motor task even if they demonstrate comprehension of instructions. Holding the communication board is to support the motor planning not to influence the responses. Only a person who has not actually paid attention to what happens between a facilitator and the person with disability to execute tasks, is likely to make that comment. Prompts have been a part of special education for years. We know it helps improve motivation and augments motor planning. Prompts are gradually faded in RPM , just like any evidence based autism therapy, with the hope that persons with disability will be independent.

3. *As opposed to revealing existing skills, RPM claims to teach individuals new skills, including advanced academic concepts (e.g., reading and spelling).*
4. *Both FC and RPM could result in the person with a disability learning to respond to increasingly subtle cues from the "facilitator" —nonetheless remaining dependent upon these cues to indicate letters.*

Response : Presuming the disabled incompetent is clearly demonstrable in the above statements that states reading and writing as advanced concepts beyond the ability of individuals with disability while they mysteriously have the capability to learn to respond to "subtle cues" from the facilitator . Such a contradictory statement only exposes the bias under which the investigators conducted their research.

5. *Further, the ideomotor effect has not been controlled in studies of FC or mentioned as a threat in the literature on RPM. Overall, the ideomotor effect remains a more parsimonious explanation for the production of the messages in both methods.*

Response: "<u>Ideomotor Effect is defined as involuntary motor movements that are performed by a person because of prior expectation, suggestions or preconceptions. It is done unconsciously</u>. " This sounds more like the Discreet Trial Interventions that my son was subjected to with an edible reward for desirable behavior. Such has certainly not been my personal experience with RPM. There is nothing involuntary about it. My son sits down for sessions only because he wants to participate. Believe me when I say that he was never a "flight risk" after starting DIR/Floortime and RPM, unlike with the previous therapies.

6. *Presumption of competency is a risk to an individual's safety when it is given more credence in treatment decisions than known facts about the individual or evidence to the contrary. That is, factual information about an individual tends to be discounted or ignored in favor of the presumption of competency of people with disabilities in general.*

Response : This is best conspiracy theory floated by this proposal. I am unable to understand the harm positive thinking has done to mankind. There are studies that show students performing better when their teachers show confidence in them and vice versa. There is no greater harm than communicating to individuals with disabilities that we don't expects much out of them!

7. *The potential harms that arise as a result of using RPM include harms associated with lost opportunity to access other evidence-based interventions and harms to the individual associated with their loss of communication rights*

Response: From my son's story I have narrated above , it is clear that the above statement is incorrect. My son did best with Interventions that don't have evidence yet , rather.

8. *The lack of evidence on the validity of RPM and its similarity in characteristics to FC (ASHA, 110 2018), as summarized in Table 1, support the conclusion that (a) RPM is a pseudoscience (Finn, 111 Bothe & Bramlett, 2005; Lof, 2015) or "junk science" (i.e., faulty information or research used 112 to advance specific interests; Agin, 2006)*

Response: Sheer refusal to truly vet a promising therapeutic intervention is condemnable. There are no specific interests that devoted parents and caring professionals have other than the very best interest in mind for their wards and clients. To assume in the contrary is willfully denying any chance at future research for these upcoming therapeutic interventions.

With these points above I refute the recent proposal by ASHA Ad HOC committee against RPM. I also believe that a formal apology is due , for the use of derogatory and inaccurate descriptions of Interventions that clearly have helped many and a sincere attempt should be made to study these interventions with an open scientific mind to help pave way for good research.

Please feel free to contact me if any specific queries.

Ludy Lukose

Email: ludyjoe@gmail.com

[REDACTED]

June 18, 2018

Dawnmarie Gaivin

Re: “Evan” and the proposed ASHA position statement on FC/RPM

To whom it may concern:

I am writing to you as a very dedicated parent of two teenage boys with autism. Today I want to tell you about my eldest son Evan who turns 15 this summer and is non-speaking due to severe apraxia. Starting at his diagnosis at age 22 months and for almost a decade afterwards I took Evan faithfully to private speech therapy anywhere from 1-3 times per week. I did this because my #1 priority from the beginning was to find a way for Evan to communicate. First, I became trained in PECS which I taught to Evan myself and had to force our in-home early intervention provider to begin using it along with me during his in-home sessions. Once in preschool he began to receive 2 hours of speech therapy per week at school as part of his IEP but I continued with the 1-3 hours of private speech as well. Come kindergarten I had to fight for an independent evaluation because it was apparent that verbal speech was a huge challenge due to his apraxia and unfortunately the school offered Evan very little in terms of Augmentative & Assistive Communication options. Once awarded the independent evaluation I was able to get Evan a voice-output communication device, the PRC Vantage Lite, which I again trained on thoroughly. I attended his school speech sessions, helped unfamiliar staff learn how to navigate LAMP, and even helped to develop implementation plans to be used across all settings. In addition to all of the above, at home we continued over the next several years working with Verbal Behavior experts trying to try to pave the most effective pathway for Evan to express himself and reduce maladaptive behaviors that were starting to become an issue due to communication frustrations. Flash forward to September of 2015 and Evan was still not using his VTL device for anything other than 1-2 word mands for preferred items, but he would gesture and use vocal approximations all day long. Sadly, due to his severe apraxia, these gestures and vocalizations were not comprehensible to most people. His IEP team was once again stumped. Having been reading about RPM for several years and, as a parent, not feeling pressured to wait for any agency to endorse my decisions, I opted to try to teach him to spell to communicate. Well guess what? My mind was blown. I took Evan to a trained provider just twice and did the rest of the work myself. Within 12 months time Evan became completely fluent – meaning, he would spell out complete sentences in response to open ended questions on a 26-letter board. First it was a stencil and then he moved on to a laminated letterboard. Currently he is working on a transferring this skill to typing independently on a keyboard which I will attach to an ipad and voice-output technology. Today Evan has not just one, not two, but three separate communication partners who work with him on a regular basis and two more are being trained. In 2017 he was finally removed from the prison sentence of a practical skills class because he had proven himself by exceling at rigorous standardized academic testing performed by an initially skeptical district team. During these assessments an independent trained communication partner (not one of his aforementioned 3 partners) worked with him on the boards. The entire team sat just feet away and could not deny the evidence that Evan was the one spelling on the letterboard. They unanimously agreed that he was not only cognitively intact but was, in fact, gifted in certain areas. And so it seems that the verdict was in. His challenge all along had been due to motor planning difficulties as a result of his apraxia, not due to intellectual disability or a lack of "motivation" to communicate. Evan's voice was finally unlocked when I addressed these motor deficits and taught him a way to use his body to properly spell out his words. EVAN'S LIFE HAS CHANGED DUE TO THIS METHOD OF COMMUNICATION. Now that he spells to communicate Evan is starting on a diploma-bound track in high school this fall. He has a means to engage with family, peers, teachers & adults and can participate meaningfully in any situation. Inclusion is now an option for him everywhere. The anxiety disorder he developed over the years of silence, causing severe self-injurious behavior during times of frustration, is slowly starting to resolve, although the PTSD of being trapped inside for so long is clearly still there. We have a way to go for full healing in that regard. In light of the above story you can perhaps understand why it is extremely disappointing to me to hear that ASHA's ad hoc committee regarding FC and RPM is not taking into consideration stories like Evan's. Is this not "evidence?" Had the committee invited professionals trained in these two methodologies to be part of their committee then a well-rounded, fully informed position statement could have been rendered. Such a statement would have been unbiased and would have taken into consideration all sides of the issue. Instead, your proposed policy does the opposite and has the potential to damage rather than protect children like Evan. The risks of silencing or re-silencing children like Evan are immeasurable. To me that is far more damaging than learning more about methodologies that have shown great results for hundreds of children that no other method has worked for. Why won't ASHA work together with the leading professionals in these other fields to find a common solution for all? Why won't ASHA help fund the specific research it is looking for so that a population of individuals who have not been well served by other methods can finally have a communication system that works? Why won't ASHA stand behind its motto to make "effective communication, a human right, accessible and achievable for all?" Please consider withdrawing your statement and issuing an apology for the damage already done to the civil rights of the students affected by the statement. In the meantime, as Evan's mom, I will continue to work with him until he is typing independently and then I will start the process over with Evan's younger brother who is minimally speaking and for whome all other methods have failed as well. I sincerely appreciate anything you can do to reverse the tide dividing practitioners and school districts from effectively serving children like mine. The proposed ASHA position statement on this topic is dangerous, unethical and biased. Thank you for taking the time to read this letter.

Sincerely,

Dawnmarie Gaivin

Mother to Evan T.

June 18, 2018

Andrew Milivojevich

andrew@tkmg.org

Dear ASHA Board of Directors and Members,

I am the proud parent of a 14 year old non-speaking autistic teenager. At the age of 2, our pediatrician diagnosed my son with autism. Before this diagnosis, my wife and I knew our son was special, but nowhe had a label. As all parents, we sought the advice of medical professionals, speech pathologists, and psychologists. Soon thereafter, and based on the recommendation of several renowned psychologists, my son entered into an ABA program until such time he attended grade school. During school hours our son was integrated into a class with the help of an education resource worker. After school we continued ABA for several years. At the time we engaged ABA, we also engaged a speech pathologist and routinely had our ABA therapists attend speech sessions. By grade 2 our son transferred into an autism class where he remained until grade 8. During this time, our son continued with ABA after school and monthly follow-up sessions with our speech pathologist. To plan for our son's transition into high school, the board's psychologist assessed our son. She diagnosed our son with a developmental disability and recommended a special needs class for mentally challenged teenagers. Our son would remain in this setting until the age of 21. Given the psychologist's recommendation, my wife and I resigned to this future course of action. By this point, it became clear that years of ABA and Speech interventions did nothing to improve our son's disposition. In 2016, things changed for the better during a visit to our pediatrician. She believed our son would benefit from learning how to use a letter-board to communicate. She explained that several of her non- speaking autistic patients had shown remarkable levels of communication. So, based on her encouragement we engaged this approach. Our first attempt at this form of communication moved us to consider using this approach seriously. So much so, that my wife and I dedicated ourselves for several weeks of training, during the summer of 2017, to become better communication partners for our son. By December of 2017, our son exhibited an incredible level of communication using a letter-board. In this same month, he demonstrated his new-found communication skills to his school board. In attendance were his school principal and class room teacher along with the board psychologist, speech pathologist, and special needs consultant. During a 1.5 hour communication session, and using his letter-board, my son answered complex questions about Smithsonian Museums in Washington DC. Once the session ended, we asked our son how he perceived the panel of school guests would react to his demonstration. He replied, "I think I blew their socks off". Today, the school board supports the use of a letter-board as a means of communication with our son. Since January 2018, two classroom aids communicate with my son daily. He has leaped several grade levels in only six months and demonstrated strong intellectual capabilities. He is no longer going into a special needs class for mentally challenged teenagers. He's enrolled in a high-school special-needs communication class. One of his current aids will be following him to high school as his full time communication partner. Starting in September 2018, our son will be pursuing a high-school diploma. The board psychologist now recognizes that our son is not a mentally challenged teenager. Rather, he is a smart young man whose outward behaviors do not represent his intellectual capacity. Had my wife and I not employed this method of communication, our son would be going into a special needs class for mentally challenged teenagers. Had our son entered into this program, it would have caused more harm than good. If there is a life lessen to be had from this experience it is this. We must first presume competence and never judge a person's intellectual disposition based on their non-verbal and outward behaviors. I trust you will embrace this letter. I also trust you will enlist the input from other letter-board users and their communication partners. I also ask that you listen to your experienced members who are communication partners for letter-board users. Ignoring the life-changing success this form of communication has garnered would be a travesty. I trust the committee will engage in thoughtful and unbiased examination of all viewpoints. Until all viewpoints can be thoughtfully considered, I strongly encourage the Ad Hoc Committee to render an apology with respect to its proposed statements. Such statements infringe on the civil right of an individual.

Most Sincerely,

Andrew Milivojevich

June 20, 2018

Anoja Rajapatirana

anojachammi@gmail.com

Dear ASHA

I cannot understand why ASHA keeps returning to this campaign of ensuring that FC is made unavailable to the very people who need such communication accommodation and are supposed to be served by your practitioners. How can we, the general public, trust such an association to have the best interests of our non-speaking children? I am the mother of a young man who has been using FC since 1991. I can tell you that we had tried a dozen or more strategies until FC entered his life. By that time he seemed destined to a future spent in a facility dedicated to the most challenging individuals. Today he is a poet, and an author and together we run an organization providing free services to others needing alternative communication strategies to express their thoughts. Let me emphasize that all our services are provided free of charge so I am not saying this for personal gain.

Do not continue this terrible campaign you are doing to render large numbers of the most vulnerable citizens speechless under the guise of looking out for their best interests is heartless and surely unethical.

Sincerely

Anoja Rajapatirana

June 20, 2018

Ayesha Ratnayake

anojachammi@gmail.com

Dear ASHA,

As the cousin of a person with severe non-verbal autism, I can advocate for the impact of facilitated communication in his life.

His parents tried many other avenues of communication and this was the only one that worked and gave him a voice after years of being mute. Today he has authored an award nominated book, co-founded a charitable foundation, been featured in TIME magazine, and in a film poem played at the United Nations Headquarters.

Preventing him from accessing this form of communication would have effectively paralyzed his chances at a fulfilling life.

I strongly urge you to cease this harmful campaign against practitioners of FC and get their input prior to initiating such damaging activities.

Sincerely,

Ayesha Ratnayake

June 20, 2018

Janani Ramanath

janani77@gmail.com

Hello,

I am the parent of a 10 year old autistic child. My son is somewhat verbal but struggles to communicate functionally. I am writing today regarding the proposed ASHA statement on the Rapid Prompting Method (RPM.)

After my son's diagnosis seven years ago, we did a few years of intensive ABA therapy. It helped a bit in some areas but also increased his anxiety severely (When you cannot do something and don't get the reward, it only reinforces your feeling of failure). We have also been to traditional speech therapy over the past 7 years and although we've been working on the same goals over and over, we have seen little progress. Therapies that have truly helped him have been physiotherapy and occupational therapy. These have helped him to function in his body better and have given us sensory strategies to help him when he is overwhelmed or in a meltdown.

We were introduced to RPM a few years ago and have been using it consistently for over a year now. This has given my son a way to show what he understands and given us a way to teach him grade level academics. It allows us to work on a variety of different goals including speech and life skills, since RPM is an educational method that goes beyond just the letterboard.

My hope for my son is that he will be able to express his thoughts and take part in decisions about him via independent, unprompted typing or writing. Indeed, several people who started on their journey using the letterboards or choices have been able to do just that.

I am concerned that that the proposed statement by ASHA is biased and does not take into account evidence from users with disabilities who use this method. It also fails to take into account input from professionals such as SLPs and OTs who have had experience with it.

Instead, it seems to be a series of poorly researched derogatory remarks cloaked in scientific lingo.

Moving ahead with this statement could significantly impact my son's life for the worse, denying him his voice and making it much harder for him to get a rich and meaningful education.

It will also create a setback from research actually being done in this area in the future by making it an unpopular area for a researcher to invest their time and effort.

Therefore I request that this statement be withdrawn and an apology issued for the damage done (by the statement) to the civil rights of individuals with disabilities.

sincerely,

Janani Ramanath

June 20, 2018

[REDACTED]

Dear Members of the ASHA Boards of Ethics and Governance,

Please find below the text of a letter I am sending today to the ASHA Board of Directors outlining my grave concerns regarding the draft position paper on RPM. I urge you to withdraw this paper, whose conclusions are not supported by evidence.

I am at your disposal to answer any questions regarding the concerns I have outlined below.

Thank you for your prompt attention to this matter.

Sincerely,

[REDACTED]

Ladies and Gentlemen of the ASHA Board:

I write to share my grave concerns with your draft position paper on RPM.

My son is a 17 year-old autistic individual who has been using a different but somewhat similar method to communicate for just over a year. The changes in him have been remarkable:

- He has begun attending regular education classes for the first time, demonstrating comprehension of grade level materials in history, health and science
- He is participating in his own medical care, for example by describing his seasonal allergy symptoms in detail to his doctor so that she can adjust his treatment regiment
- Incidents of yelling, knocking chairs to the floor when frustrated, pulling hair when in physical discomfort of pain – which used to occur several times a month – have all but ceased entirely, with just a 2 incidents this entire year, both when suffering intense sinus pressure
- He is now actively choosing leisure activities. His favorite movies this year were The Darkest Hour and The Post, both of which he was able to discuss with other movie lovers.
- He has made friends, with whom he can draft both advocacy plans and simply trash talk. He is able to communicate with 7 different partners who have been trained in this approach, and his comments include the same stylistic touches regardless of who is working with him. (In other words, if we are each manipulating his answers, we're all working from a hell of a detailed unwritten style guide.)

We have invited his developmental pediatrician, long-time SLP, long-time BCBA as well as a local neuropsychologist in to observe him communicating. All expressed some degree of skepticism prior to coming. All left their observations amazed. Several were specifically looking for reasons to question the validity of the method and, by their own account, actively looking for signs the partner was influencing him. They found none. His SLP has now incorporated this method in her sessions with him and has redone some of her initial evaluations, the difference in his scores are dramatic. The neuropsychologist conducted psycho-educational testing allowing Alex to use this method. She, too, reached very different conclusions about his abilities than previous evaluators using traditional methods. Both have put their findings in written reports and shared them with our local school district.

Three individuals from the school district have also come to observe his sessions and have agreed that he can communicate to a far greater extent using this method than any of the many tried previously (PECS, ProLoQuo2Go, and many years of both standard speech therapy and Verbal Behavior/ABA).

Your draft position paper strikes me as problematic on three dimensions:

1. You review the existing research and find it not well-designed enough to support the conclusion that the individuals with disabilities are communicating their own thoughts. However, by definition, if the research is not well-designed, you cannot draw ANY conclusion from the findings, including that the thoughts are NOT those of the individuals with disabilities. Your assertions that the communication is not authentic is

unsupported by evidence. A more constructive approach to declaring the method invalid would be to describe what you view as more appropriate research protocols.

2. Even more egregious in my view is that fact that you made no effort to actually observe or interact with individuals who use RPM or similar methods to communicate. How can you possibly declare these methods invalid without any direct empirical observation? This seems the antithesis of the scientific method.
3. Finally, your attack on the presumption of competence is at odds the U.S. jurisprudence. When a motion is filed to have someone declared incompetent, the burden of proof is on the moving party to prove to the courts' satisfaction that the individual is incompetent, NOT on the individual to prove their competence. You are essentially suggesting that non-speaking people should not benefit from the same civil rights as their fellow citizens who can speak.

I respectfully ask that you withdraw the draft position paper.

Sincerely,

[REDACTED]

June 20, 2018

[REDACTED]

Dear ASHA decision-makers:

I understand that a rogue Ad Hoc committee is presenting statements that delegitimatize Facilitated Communication and Rapid Prompting Method as techniques to use with specific segments of the nonverbal population. This is outrageous! This is not who you are nor who you should be!

My 12-year-old son has severe autism and has only very minimal language. He also has poor motor planning and several disruptive behaviors, especially when frustrated. He has violently resisted all manner of verbal behavior, sign language, assistive communication devices--you name it. The ONLY technique he has responded well to has been Facilitated Communication. Despite his affect of being that of a five-year-old child, his intellect has emerged when introduced to FC, and he has typed messages of profound thinking and perception. I realize that many are skeptical and suspicious of these results, even when they have been eye witnesses to FC and/or RPM exchanges. However, I know that my son is the only one influencing the message, and not the facilitator, because of direct evidence and my own observation. For example, we have asked my son to type answers with an independent facilitator to questions that this person knew nothing about (e.g., the multiple colors of rooms; the specific TV channel watched at home, specific newscasters preferred, etc.). I have also facilitated my son's typing where he directly typed requests and comments about topics I had no idea about.

Please do NOT deny access or malign these methods that require human support! Put in place whatever safeguards, chaperones, double-checks, etc. that may be necessary, AS IS TRUE OF

ANY THERAPY where the recipient is a vulnerable person who cannot independently express himself nor describe his own experience. If you have doubt, give the nonverbal person the benefit of it! Please do NOT remove what is often the only means these individuals have to express what is otherwise LOCKED IN. To do so is brutally cruel and reflects an absolute lack of empathy. My personal "agenda" is for the nonverbal person to be able to communicate in whatever way suits their own set of abilities and preferences. No one should be able to deny this most basic human right of communication and relationship.

Please withdraw proposed statements about FC and RPM! Then, please apologize for the heartache and harm these vicious, unfounded words have already caused to people who cannot defend themselves nor their own interests.

Sincerely,
[REDACTED]

June 19, 2018

Erin C. McAlister
Ellenwood, GA 30294

Ecmcalister64@gmail.com

Dear ASHA Board of Directors:

I understand that, recently, ASHA (upon recommendation by an ad hoc committee) published proposed position statements on FC (Facilitated Communication) and RPM (Rapid Prompting Method). If finalized, these statements could have severe repercussions for individuals who use these methodologies to communicate effectively.

I am the parent of a 15 year old autistic girl, Catherine, who was diagnosed with apraxia of speech at an early age. Currently, she uses a no-tech letter board in order to spell what she wants to say correctly and consistently. Using the letter board enables her to excel in grade-level curriculum at her high school.

I believe that policy decisions of such magnitude should involve a careful and unbiased examination of viewpoints. I urge you to consider input and evidence from users and ASHA members with experience in these methodologies. This should be done` before issuing a statement that could have detrimental effects on individuals’ lives by limiting access to any/all effective forms of communication.

Sincerely,

Erin C. McAlister
Ellenwood, GA 30294
Ecmcalister64@gmail.com

June 20, 2018

[REDACTED]

To the Board of Directors ASHA,

I am writing to you in regards to the proposed position statement by ASHA's Ad Hoc Committee on Facilitated Communication (FC) and Rapid Prompting Method (RPM) to which I strongly disagree.

My husband and I have a 10 year old daughter with autism who is considered at best a minimal speaker but generally is considered non speaking. She also has dyspraxia which is exceptionally common for children on the spectrum. From age 2 to age 8 we have undergone intensive Applied Behavioural Therapy (ABA) and traditional Speech Language Therapy (SLT) services. Our daughter has also been availed of a specialist teacher within a mainstream classroom environment and a full time teacher aide. Numerous attempts to facilitate communication such as PEC's and use of technology have been unsuccessful.

In late 2016 we decided to try using letter boards and started with the stencils, very much in line with RPM methodology. Our daughter struggled at first, but she struggles with everything, so we don't let that deter us. To begin we needed to heavily prompt her - gestural and verbal. We considered this 'coaching her motor skill' and continued to believe that she did understand the lessons we were reading to her and that she wanted to learn. This was not an easy process and some days she felt very frustrated - as did I ! Slowly however over time we saw improvements and were able to reduce our prompts and move to a 26 stencil board (having started on 3 boards with the alphabet split) and we have now moved to a laminated board.

The ability of my child to demonstrate her cognitive ability and to have a 'voice' has without doubt led to a happier child who is now treated with more respect and inclusion than we could have dreamed of. Whilst at a mainstream school, until this year much of the school day for her was held outside of the main classroom on the assumption she couldn't comprehend what was going on and when in the classroom her work was close to kindergarten level and not age appropriate. Many melt downs were held in class and we assumed she couldn't cope. Now her work is the same as all of her peers she is settled and calm in class and melt downs are close to non existent.

The ASHA Ad Hoc Committee seems concerned with the assistance of a facilitator and the verbal and gestural prompting of RPM. How can this be ? Every professional I have used whether ABA Trainer, Teacher, SLT or OT has encouraged a facilitator to assist with learning something new and has included verbal and gestural and physical prompts. I think about the amount of prompts and facilitator help (hand over hand) needed to teach my daughter to wash her hands. Over time we faded prompts and this task can now be completed independently by my daughter. Using letter boards is just the same. Heavy prompting to start and fading over time to allow independence.

ASHA's claim that there is no scientific evidence to support RPM is quite a leap to calling it junk science.

If this position statement by a group of clearly biased individuals is endorsed I consider it a breach in my child's human right to be able to effectively communicate.

I am asking that ASHA withdraws the proposed statement immediately and issues a formal apology for what negative impact this proposed statement has already had on the right to communicate for individuals with disabilities.

Yours sincerely
[REDACTED]

June 20, 2018

Susie Lotharius

slotharius@gmail.com

Dear ASHA Board Members:

It is so hard for me to live my life to the fullest each and every day because of my severe motor planning challenges. These mostly impact my speech, but also impact the way I use my body to interact with my environment. It is the most frustrating thing to not have total control over your body. Stephen Hawking's body did not work well but his intelligence took him far. Why is it hard to believe that I am in the same situation but have been trapped in a broken body since I was little, and had not yet had the opportunity to show my intelligence to the world?

There are many individuals that use alternative ways to communicate their intelligence to the world. This is my only way I have to write letters like this to make my voice heard.

Have you ever had anyone question your intelligence or the words that come out of your mouth? I guess that it is not normal for you to experience this, but it is my norm. Using a letter board to make my voice heard is laborious and is hard work but it is my only option right now that works for me. Your proposed position statement on RPM is going to possibly take this away from me and from others in the same boat as me. It is hard to believe that these hard earned words that I spell are not seen as real because I need someone to hold the letter board and prompt my body to sustain through my thought. I wish I could spell independently and I am trying, but it takes my body so much time and rigorous practice to gain automaticity.

What is not okay is that there is not more opening of minds to the truth of the potential within me and others like me. This is going to be a significant loss to the field of mathematics if my means of communicating is taken away in an educational setting because of this proposed position statement.

It is about time that words that are painstakingly created from the minds of non speakers by pointing to letters one at a time are seen as valid and true. Each and every individual has the right to make his voice heard in this country, but your proposed position statement would possibly get in the way of enabling some to take advantage of this right.

I want to encourage the ad hoc committee that is in charge of this proposed position statement on RPM to reconsider and to issue an apology to those of us who are able to communicate now thanks to RPM.

Many non speaking individuals are not reaching their potential because of thinking that is not accurate. You have an opportunity to make this right and to stand up for the communication rights of many of the individuals served by the members of your organization.

Thank you for your time and consideration,

A non-speaking self advocate

June 20, 2018

Rhema

jeneilrussell@yahoo.com

Dear ASHA,

My name is Rhema and I am autistic. I was trapped in silence for twelve years. My autistic body would not obey my intelligent mind. To be totally stuck in your own head is a nightmare. Sometimes I hurt myself and did destructive things because I was so absolutely frustrated. The one hope I had was one day that I would have a voice bigger than I could imagine.

My mother took me to learn RPM and this was the moment I was sure I would be able to speak one day. It took a lot of work but I learned to make my finger point on my letterboard and keyboard and I learned to also listen to the letters in my head.

Now I am able to share my thoughts. Now I am able to study strong subjects in school. Now I have two friends that I can talk to. Now I have education opportunities I never had before.

Imagine how disheartening it is to hear that your organization would say that my means of communication is not valid and is even harmful. How can you say that I am not the author of my own thoughts just because I need support? How can you say that the thing that has freed me from a prison of silence is a hoax? I hope you will reconsider your position. I hope you will not jeopardize the chances of others to have their voices heard. I hope you will listen.

Sincerely, Rhema.

June 21, 2018

The McMahon Family

To whom it may concern,

The American Speech-Language-Hearing Association (ASHA) position paper on RPM is deeply flawed. It attempts to debunk RPM by stating that it is similar to Facilitated Communication (FC) and that there are no studies that show it to be successful. Because something hasn't been shown to be good does not mean that it is bad; and because two things are similar does not mean they are the same; this is faulty logic. The position paper also states that there are no studies that prove authorship in the use of FC when in fact there are numerous studies that do just that (http://soe.syr.edu/media/documents/2011/6/Research_Supporting_Authorship_version_22.pdf).

Soma's son clearly demonstrates his ability to communicate in the "60 Minutes" story. This method is simply a way of teaching children to communicate by spelling — initially; and then progressing to writing or typing. Complicated motor control is a common symptom of autism and other developmental disorders. Speech is difficult. Spelling, on a letter board or keyboard, is a considerably less complicated way of communicating. Soma was her son's teacher. RPM was the method she used. She has taught others to do the same. Others have learned to communicate independently with this method. Why would you then deny others of the same opportunity?

Denying individuals the opportunity to learn via RPM or any other alternative technique only serves to continue silencing their voices. When Anne Sullivan started teaching Helen Keller by spelling on her hand there was no scientific proof of this method. If she was teaching today she would be shunned via positions such as this and prevented from teaching. This position represents a continued tragedy for the individuals who's voices have been silenced by autism and other development disorders.

Respectfully,

The McMahon Family

June 21, 2018

Nafisa Chalchal

nafisachalchal@hotmail.com

To whom it may concern

I am a mother of a 22 years old daughter with Autism. She has a very minimal expressive language and is not able to converse. Ten years ago, we realized that she can press letters on a hand –held device if given support to her wrist. We purchased an AAC device and sought some training as the facilitator. We contacted Syracuse University's Institute on Communication and Inclusion and received quality training.

I had tried many interventions in the past such as PECS (Picture Exchange Communication System), Gateway communications developed by Speech and Language Therapists, but found all of them to be very limiting in their scope. My daughter was suffering from depression at the time, which got better when we first established the communication through Facilitated Communications. I consulted with a team of experts in our home town, including an occupational therapist and speech and language therapist. They verified that it is her, who is typing, after examining how communication occurs between us and our daughter. She was able to finish high school courses with her peers using Facilataed Communication where support was provided by the class teachers who accepted her work as her genuine work not of her facilitators'.

My daughter is able to convey her likes and dislikes to us, she is able to answer emails and is hopeful to attend a university based program using Facilitated Communication. If facilitated Communication is taken away from my daughter than it will be equivalent of taking away cane from a blind person.

I urge the ad hoc committee of ASHA who wants to implement the proposed policy regarding the Facilitated Communication to take into account the experiences of people whose lives have dramatically improved because of FC. Input from those professionals who have experience in working with people who have difficulty in expressing themselves and are also suffering from motor functioning and hand and eye co-ordination deficiencies, using FC, should be taken into account.

The proposed policy regarding the Facilitated Communication is a great concern for my daughter, my family and countless other people who rely on this method of communication with their family members and clients who otherwise are not able to express themselves. My daughter is very anxious about her future because of the fear of rejection of the method of communication that she relies on, if the proposed policy comes into effect. Such an action will be a threat to her civil rights as a human being.

I urge the ad hoc committee of ASHA to withdraw the proposed policy regarding the facilitated communication. I will also like to see more un-biased research in the areas of the Facilitated Communication.

Thank you,

Nafisa Chalchal

June 21, 2018

Killian Hynes

bhynes666@gmail.com

My name is Killian and I am a 17 year old Junior at Mira Costa High School who relies on the assistance of a Communication Partner ("CP") to express my thoughts. I also rely on an assistant to dress, tie my sneakers, unzip a sweatshirt, and all manner of other life tasks that require motor initiation and coordination. I can walk but I cannot scream, even when faced with intense pain. The reasons for this signal disruption in my brain are unknown; I have been seen by many medical experts who have reviewed countless tests, images and labs in search of the culprit behind this mixed up state of being that constitutes my life. However, I can think, I do have preferences and I can learn. In order to enjoy my existence, develop my education and experience peace with this universe, I need help with organizing my jumbled being.

I have loved and am Facebook friends with many of the kind professionals who have provided me with thousands of hours of speech therapy since age 2. I still see a speech therapist to this day. I have had spent years engaged in hour after hour of ABA; PROMPT, RDI, Floortime, Vince Carbone therapy and plain old speech therapy (complete with spoonfuls of peanut butter): tragically to no avail. My parents have prioritized nothing over trying to engage experts that can help restore my capacity to verbalize my thoughts. To this day we remain hopeful someone somewhere will innovate a solution for me.

In the meantime (that messy interminable waiting period), I need to further my education and navigate everyday life -- which translates to My Need for Near-Constant Motor Assistance. This is humbling beyond the imagination of most people.

Thanks to open minded influencers in my early years, I always was able to participate in Gen Ed curriculum and environments — including Montessori pre-school and kindergarten. Watching the other kids sitting on the floor picking up individual letters and arranging them into floor-words gave us the idea - long before the iPad was conceived - that there was a way for me to tell others what was on my mind, one letter at a time.

Being able to access letters with the help of a trusted partner is central to others being able to visualize my humanity. Our family experiences this reality over and over again - - People who don’t know me meet me and form an impression only to then see me in class or read my writings and the “aha moment” is visible to the point of physicality.

I fail to see the difference between me and my CP working together and my friend’s assistant who pushes him in his wheelchair around school. Or the aide who helps a blind student navigate our crowded, uneven high school campus. Or the service dogs who calm a veteran injured during war.

What is the motivation in trying to question our emerging voices by what has been described as a rogue group at your organization? Why would anyone - - much less a group supposedly dedicated to accessing effective communication - - go out of their way to obstruct Justice?

We beseech the higher aspirations of the thousands of kind speech therapists to rise up and speak up and reject this abhorrent, humanity-depriving point of view.

Respectfully,

KJH

June 21, 2018

Jean Trainor

Dear Board Members,

I am writing regarding your proposed position statement on facilitated communication. As Nate's mom, and an advocate for people with disabilities, continuing the debate on facilitated communication is disappointing. Nate and I believe in everyone's right to communicate and this debate denies individuals the right to communicate. The key to this debate is really if we believe people are competent. Facilitated communication challenges the belief that people with disabilities are incompetent.

There is no harm in presuming competence and allowing people to try new, innovative, methods of communication. For many, traditional methods of communication have been unsuccessful. As Maya Angelou said, "we now know better, so we must do better."

Nate and his assistant had a very in depth conversation about people who do not believe in facilitated communication. He typed these words out "afraid of change or the unknown, and people CHOOSE not to believe it." He asks "who would want anyone to not have a voice?

Why do people not believe in FC? Why would they not want people to have a voice or be able to communicate? This is just immoral, unethical and WRONG. What if the unbelievers were in a reverse situation where they couldn't speak? Would they still not believe?"

Nate & I encourage you to withdraw the proposed statement. As for Nate and I, we are going to live our lives and leave the debate to the researchers.

Sincerely,

Jean Trainor

June 21, 2018

Nika Abrarova

nosik24@hotmail.com

Dear ASHA board of directors:

We would like to share with you the story of our son who was diagnosed with PDD NOS at 22 months old and made significant progress by kindergarten with conventional therapies. He appeared happy, bright, and creative with a rich imagination and a unique sense of humor with early self taught reading and writing skills. He was thriving in the integrative setting at school until kindergarten. However, all of that disappeared in a short period of time when our little one hit a mysterious regression, and by the age of 6, became almost completely mute, unable to hold his pencil to write but preserved some reading skills. By the recommendation of a child study team, he entered a self-contained ABA classroom and initially seemed happy there. He was retaught how to say his name, address, and phone number, but unfortunately, years went by, and our son continued at the same academic level for 4 years, and in fact, hit behavioral regression. The last school evaluations showed poor performance due to his unreliable verbal responses. An independent neuropsychological eval confirmed his poor verbal and writing performance even though his nonverbal IQ remained within the normal range.

We came across RPM by recommendations of other parents when our son was almost 8 y/o. We saw results in a few months; our son effortlessly caught up in his academics and was evaluated by an SLP in the fall of 2017. He scored above his chronological age in language based on his output on the letter board and laptop. Interestingly, during the speech language eval, our son's verbal responses were very close in meaning to his typed ones. For example, during the test, he would say "camel foot" when shown a picture and then type "hoof" or say "garden"or "house" and then type "greenhouse." In conventional speech evals, those verbal responses would not be counted as correct. When our son does math with RPM, he verbally says the correct responses while pointing on the numbers and functions on the alpha numeric board. These objective facts convinced us and our private educators and evaluators that his typed responses are authentic and reflect his impaired motor planning which affects his speech rather than cognitive deficits. After three years of RPM, at the age of almost 11, our son is showing significant progress in his speech and uses sophisticated vocabulary verbally as he is exposed to rich academic content through RPM. For example, he uses metric units of measurements with his requests, like "I want 50 grams of baking soda" or "5 ml of olive oil in my salad." When asked what he studies at school, he answers "language arts", "social studies", etc. He is still not conversational, and the only way he can express his thoughts in depth is through his typing. During three years of RPM, our son progressed to independent typing on his laptop without anyone holding or touching it; he still needs encouragement from his teacher or a parent to keep going while typing, but we are hoping that in a few more years, our son won't require even that minimal encouragement from his teachers to stay on task and focus. We are also working on our son's independent functional handwriting, reading aloud, and life skills using the principles of RPM and made significant progress in that area as well. Our SLP and educators are seeing results first hand with this methodology and keep supporting his progress through RPM. Our ABA therapists, on the other hand, refuse to support this methodology as it is not research based.

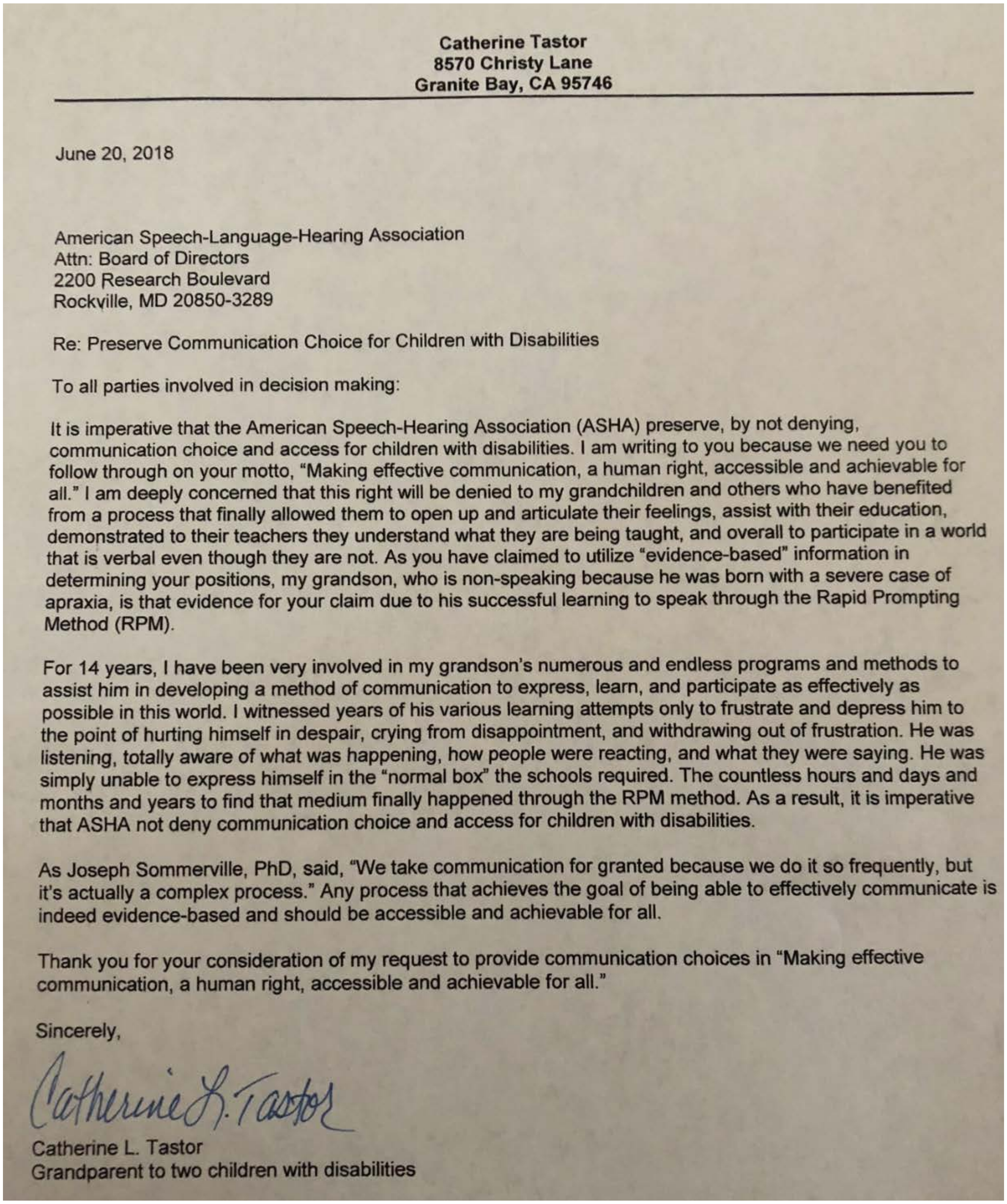
We are sure you will hear multiple similar stories from other parents. Please reconsider your stance on RPM and allow practitioners to use their professional judgement and use methodologies in their practice that suit each individual child, whether it is research based or not. We do not think that professionals should encourage all the parents of children with impaired communication skills to try it as it is not evidence based, but if they see that this methodology brings positive results in current users, it should be supported 100%. If you allow professionals to use their judgment, they will be able to collect long-term data and see where children currently using RPM will end up in the future. We have hope that our son will be able to keep up with the huge academic load in middle and high school with the help of RPM in spite of his poor conversational skills. He may be able to enter college and eventually acquire a profession and be able to support himself, not having to rely on taxpayer money. It will sadden us if this opportunity will be taken away from our son; he would no longer have access to age appropriate education on the mere fact that RPM is not research based. Didn't patients with cerebral palsy, Parkinson's disease and other movements disorders, Helen Keller, and Steven Hawking use assistive technology and a letter board to express themselves? That practice has been known for decades and proved itself historically to be effective and perhaps should be "grandfathered" and exempt from short term scrutiny. If RPM is a fad, it will not survive for a long time and will vanish spontaneously, but if it is effective, it will thrive despite all the artificial barriers. RPM has been around for over 10-15 years and is spreading rather quickly. There is a huge demand on the part of families, and professionals need to keep up with that demand. Progress will continue in spite of everything and will survive all obstacles.

Sincerely,

Jeffrey and Nika Stirling, MD

June 20, 2018

Catherine Tastor



Catherine Tastor
8570 Christy Lane
Granite Bay, CA 95746

June 20, 2018

American Speech-Language-Hearing Association
Attn: Board of Directors
2200 Research Boulevard
Rockville, MD 20850-3289

Re: Preserve Communication Choice for Children with Disabilities

To all parties involved in decision making:

It is imperative that the American Speech-Hearing Association (ASHA) preserve, by not denying, communication choice and access for children with disabilities. I am writing to you because we need you to follow through on your motto, "Making effective communication, a human right, accessible and achievable for all." I am deeply concerned that this right will be denied to my grandchildren and others who have benefited from a process that finally allowed them to open up and articulate their feelings, assist with their education, demonstrated to their teachers they understand what they are being taught, and overall to participate in a world that is verbal even though they are not. As you have claimed to utilize "evidence-based" information in determining your positions, my grandson, who is non-speaking because he was born with a severe case of apraxia, is that evidence for your claim due to his successful learning to speak through the Rapid Prompting Method (RPM).

For 14 years, I have been very involved in my grandson's numerous and endless programs and methods to assist him in developing a method of communication to express, learn, and participate as effectively as possible in this world. I witnessed years of his various learning attempts only to frustrate and depress him to the point of hurting himself in despair, crying from disappointment, and withdrawing out of frustration. He was listening, totally aware of what was happening, how people were reacting, and what they were saying. He was simply unable to express himself in the "normal box" the schools required. The countless hours and days and months and years to find that medium finally happened through the RPM method. As a result, it is imperative that ASHA not deny communication choice and access for children with disabilities.

As Joseph Sommerville, PhD, said, "We take communication for granted because we do it so frequently, but it's actually a complex process." Any process that achieves the goal of being able to effectively communicate is indeed evidence-based and should be accessible and achievable for all.

Thank you for your consideration of my request to provide communication choices in "Making effective communication, a human right, accessible and achievable for all."

Sincerely,

Catherine L. Tastor

Catherine L. Tastor
Grandparent to two children with disabilities

June 21, 2018

Ruth Carrick

rcarrick@iinet.net.au

"I believe a committee of ASHA is in the process of disclaiming facilitated communication (FC) as an effective means of communication by non verbal communicators. Please know and be assured that FC has changed my non verbal granddaughters life. As her guardian it was through FC that she told me how unhappy she was at a particular day service. I was able to change that situation immediately. Through FC she has for the first time in her life made (unpaid) friends with her peers. Through FC she has been able to make choices previously denied to her. FC may not be the best means of communication but when it is the only means of effective communication believe me it is WONDERFUL. Do not relegate our non verbal folk back to dependence and silence. Sincerely, Ruth Carrick, Queensland, Australia"

Thank you,

Regards,

Ruth Carrick

June 19, 2018

Seanon Jones-Kirsebom

seanonjk@telus.net

RE: ASHA's AD Hoc committee position paper regarding the Rapid Prompting Method

My son types independently, and every professional who interviews him (pediatricians, occupational therapists, psychiatrists, speech-language/AAC professionals, physical therapists), recognizes that he is typing his own thoughts. He had medical reports which confirm this fact. I am writing to express my strong opposition to the AD Hoc committee position paper ASHA is proposing, which will prevent non-speaking people access to communication and education which is their human right.

When my son was 14, he learned to communicate fluently. Initially, he learned to spell out his thoughts by pointing to letters on a printed card. After much practice, he was able to type independently on an iPad or keyboard which sits on a table. No person touches my son, nor his iPad or keyboard as he types. As a result of this ability to communicate, my son is successfully working towards high school graduation.

Prior to being able to type, my son had spent more than 12 years in an intensive ABA program, and worked with an SLP on vocalizing speech. He was directed to using PECS to express wants, and to practice rote phrases, such as, "I like the pool," under the direction of a behavior interventionist. Despite my son's efforts, he was not able to reliably express thoughts beyond memorized sentences, and food items. He became very frustrated.

When he learned to type, my son wrote that his autism can be explained by:

1) Difficulty with intentional body/mouth control

2) Extreme sensory overload
3) Overwhelming anxiety

Over the past two months, my son has participated in a comprehensive assessment at our city's autism assessment center, in which he was interviewed, tested and observed by a developmental paediatrician, a developmental physical therapist, a speech and language/AAC specialist, a school psychologist, a psychiatrist and an occupational therapist. The unanimous conclusion by the assessment team was that my son is affected by challenges in voluntary motor movements, low muscle tone, anxiety and a sensory system which causes him to avoid certain sounds, lights, crowded places, etc. Once my son's physical symptoms were accommodated for (he was able to type and point to answers independently), he tested in the "above average intelligence" range. The team, while aware of the FC and RPM controversy, observed absolutely no influencing of my son's typing. The words my son typed, it was concluded, are authentically his own. Despite my son's difficulty with vocal speech, it was concluded that my son was well able to express thoughts that were consistent with his chronological age.

When I became aware of ASHA's proposed position, I realized that this position will be used as "proof" that non-reliably speaking people are intellectually incompetent, and they will be further marginalized. Imagine that this position is used to prevent a legitimately communicating person who cannot speak from advocating from themselves. This is a strong position on ASHA's part, as on scrutiny, much of the paper is based on incorrect information regarding RPM, and flawed, misleading research methods. Furthermore, this position paper ignores non-speaking individuals who progress to independent typing (which is completely possible, as prompts are faded, just as in ABA). My son is someone who is known to have progressed to independent communication. Despite his communication and intellect having been assessed and authenticated, it is quite possible social workers in the future will use ASHA's position as a means to prevent my son from advocating for himself.

This proposed position is counter to your vision statement – "Making effective communication, a human right, accessible and achievable for all." Adopting this biased AD Hoc Committee position denies the rights of non-reliably speaking people to modes of communication which take motor differences (which are well supported by research), into account. The deliberate refusal to consider the perspectives of non-speaking people is a precarious position, at best, as research into non-speaking autism is becoming more widely understood. Please review, for example, "Autism: The movement sensing perspective," edited by Elizabeth B. Torres and Caroline Whyatt. This text links sound scientific research to movement differences in autism, and contrasts the subject's internal state with external behavior. Failure to acknowledge movement differences in autism is negligent, particularly as people on the autism spectrum repeatedly report this as a core symptom which limits communication. I am aware than many, many professionals and parents are writing to ASHA to express their strong opposition to the AD Hoc committee's proposed position. ASHA, thus, cannot ignore that professionals from varying perspectives agree that non-reliably speaking autistic people are capable of communication by accommodating for motor planning and movement initiation difference—and for anxiety. You have information which is direct opposition to the proposed AD Hoc position, and I ask that you do not ignore it.

Sincerely,

June 22, 2018

Daniel and Elizabeth Zielinski
Chantilly, Virginia 20151

elizabeth.zielinski@gmail.com

American Speech-Language-Hearing Association
Attn: Board of Directors
2200 Research Boulevard
Rockville, MD 20850-3289

Dear Directors:

We are writing to you today in response to the draft position statements issued by ASHA's Ad Hoc Committees on Facilitated Communication (FC) and Rapid Prompting Method (RPM). We are the parents of a 12-year old minimally and unreliably speaking person.

Our son began receiving speech therapy at the age of two, when he was diagnosed with childhood apraxia of speech (later expanded to autism spectrum disorder). He consistently received several hours of speech therapy per week, delivered both privately and in the public school setting, from the ages of 2-11 (fifth grade). He also received many hours of applied behavioral analysis (ABA) weekly, delivered both at home and in ABA-based classrooms.

Over those years he was evaluated on two separate occasions by two different school-based AAC specialists (in second grade and again in fifth grade) and both determined him to not be a candidate for a device due to his minimal speech. When he was six, his ABA therapist attempted to teach him to use a PECS system but could not achieve reliable usage of it. As a family, we also attempted to teach ProLoQuo using principles of ABA as supervised by a BCBA, with little success. On multiple testing occasions for spoken intelligibility administered by licensed speech-language pathologists, he has not exceeded an estimated 56% intelligibility rating.

He has been medically diagnosed with an anxiety disorder which manifests as self-injurious behavior. His ABA therapist completed a Functional Behavior Assessment (FBA) and clearly identified his inability to communicate effectively as the antecedent to his self-injury.

We began using a letter board for his spelled communication in March, 2016. From April 2016 to March 2017, his measured incidence of self-injury (as documented in his ABA-based classroom) reduced from an average of 30 times per four-week period down to 12 times, a decrease of 60%. He was not receiving private speech or behavioral therapy during that year.

He participated in a recent medical appointment with his doctor (a psychiatrist, trained in both behavioral disorders as well as medicine) by spelling his communication with her on a letter board. By doing so, he was able to make a meaningful contribution to health care decisions being made on his behalf. This was a goal that had been unachievable using other forms of communication support. His doctor watched him carefully while he spelled his responses, and in her judgment, his comments were authentically his own.

Should his preferred method of communication be taken from him based on ASHA's recommendations, we have evidence to expect that his self-injurious behavior would increase. He would lose his basic human right of communication as well as a measure of personal safety. Furthermore, many families in addition to ours are at risk of losing support from professionals, educators, school systems and insurance companies based on ASHA's recommendations. Our son's cognitive abilities, as expressed through his communication method, could be disregarded. He is at risk of losing access to the world; and with it, his chance to live a full and independent life of his choosing.

We are disappointed that the group of individuals ASHA selected to develop this position statement does not include anyone with direct experience in the methodologies in question. The Ad Hoc Committee is comprised of individuals that have made publicly documented, disparaging comments about the disabled individuals who use these methods; and have personally attacked parents, caregivers, professionals and educators who support these individuals. This position statement was not drafted by unbiased individuals, and it did not consider multiple viewpoints in reaching their recommendations.

We fail to understand how a credentialing organization such as ASHA finds the draft position statement to be an acceptable representation of their mission. It is factually inaccurate in parts, uses pejorative language, and makes false claims of having done comprehensive consideration of the methodology.

We do agree that more research is required, but supporting data is already available across complementary topics (just one example of many can be found here: http://www.dsq-sds.org/article/view/1060/1225). Broadly dismissing these methods in the terms your Ad Hoc Committee has used will prevent further, more specific research from ever being done. The implications to that are potentially tragic.

We are asking for the following: 1) that the proposed statements regarding spelled communication be withdrawn; and 2) that ASHA issues a formal apology for the damage that has been done by these statements to the civil rights of individuals with disabilities.

Thank you for your consideration. We look forward to receiving your response.

Sincerely,

Daniel and Elizabeth Zielinski

June 23, 2018

Chantal Sicile-Kira

http://autismcollege.com/blog/2018/06/23/proposed-asha-position-statement-rapid-prompting-method-rpm/

Dear ASHA Board of Directors:

My name is Chantal Sicile-Kira and I am the author of five books on autism, an International speaker, and I am known for my practical advice to parents and educators. Many years ago, I worked for two years at Fairview State Hospital (now called Fairview Developmental Center) and taught functional and community living skills to the first group of young adults in preparation for de-institutionalized following the passage of the Lanterman Act. I also worked for a short time at Orange County Regional Center as a case manager to families of children with developmental disabilities.

As well, I have 25 years of experience in non-profit leadership roles related to autism, including two years as Co-Chair, South Counties Autism Regional Taskforce, reporting to the California Legislative Blue Ribbon Commission on Autism, and two years as Member, Taskforce on Transitional Services & Supports reporting to the California Legislative Blue Ribbon Commission on Autism. I am also the parent of Jeremy, a 29 year old who learned academics and communication skills using RPM (The Rapid Prompting Method), and continues to do so as a fully-included productive individual with a number of trained communication partners.

I respectfully encourage ASHA to withdraw the proposed position statement in regards to RPM. I am very concerned that The Ad Hoc Committee has refused to consider input or evidence from users and ASHA members with experience in these methodologies. Such important policy decisions should involve a careful unbiased examination of different viewpoints. I believe that more research is indeed needed. I also believe that a professional or parent trained in the methodology is capable of making a decision on whether or not a method is worth trying with a certain individual, and then verifying success or not on a case by case situation.

I share my experience below with my son's permission. We hope this will enlighten you as to how for certain individuals, RPM can be an effective method of academic and communication skills.

While doing research on educational methodologies and medical interventions to write my books, I read about the evidence- based practices that were considered effective. I also learned about educational methodologies and medical interventions that did not yet have research evidence, because no research had yet been done. However, some of these interventions were effective with some individuals. As a parent and autism professional, I believe that there are practices that can be tried and validated on an individual basis. RPM is one of those.

I first heard of RPM when doing the research to write one of my books, Autism Spectrum Disorders (2004 Penguin, Autism Society of America, Book of the Year 2004; Revised-edition 2014 Penguin). I decided to try it with my son, as it made sense for him and his challenges. Jeremy received direct instruction from Soma Mukhopadhyay (at the time living in LA) twice a month, and I practiced with him every day for half an hour. We did this for approximately two years.

When Jeremy was born he was hypotonic. He needed physical therapy to learn to sit straight, and to use his arms and legs. Every time he learned a new skill (ie eating with a spoon or fork) he needed hand over hand prompting. He had speech therapy as a toddler, but it was not effective (again, muscle tone challenges). When he was 5-6 years old he had a supervised home-based ABA Lovaas program. I did ten of the 40 hours of ABA therapy a week myself, which meant I learned about how Jeremy learned – or didn't learn.

Jeremy learned to identify and correctly label verbally over 100 pictures. However, if you put the pictures in front of him, he could not give you the correct picture requested at a 80-100% success rate. Since he could verbally identify the objects introduced to him one by one, we knew he had receptive language. When he was 7 PECS was tried both at home and school. He communicated using a sentence for first time using the "I want… " sentence strip plus icons in a binder (iPads did not exist till he was out of high school). He had a difficult time choosing the icon out of the binder books and putting it on the strip (vision processing and motor challenges). He never progressed past the "I want" sentence. Professionals over the years described Jeremy as having challenges similar to a person with CP. He continues to have sensori-motor challenges and visual processing challenges, although these have improved over the years with exercise and therapy.

Therefore, when I heard about RPM, it sounded like something that was worth trying with Jeremy. Success was slow, but obvious. It was not a "magic pill" and it did not cure his autism – but that was not my goal. My goal was effective communication with a variety of communication partners for use in daily life and with living skills, and to allow him to make choices and decisions, to blossom as an individual, and have a productive life as an adult.

When Jeremy was in high school he began using RPM at school with a variety of communication partners trained and supervised by a Speech and Language Pathologist trained in FC who understood the strategy of RPM.

Jeremy graduated from high school at age 21 with a full academic diploma. He auditioned for, and was chosen to give a commencement speech at graduation. During his high school years he was able to participate in general education classes, as well as a class in journalism. In his English classes and his journalism class, Jeremy learned effective writing skills and his love of writing to share his thoughts and opinions. He was asked to write a monthly column for the school newspaper.

More importantly, Jeremy was able to communicate appropriately and effectively when he was sick or in pain. He was able to make choices and life impacting -decisions and tell us what he was feeling. Thanks to learning communication skills via RPM, Jeremy now has a full and productive life, fully – included in his community. For more details in regards to his accomplishments since high school, please read his attached resume. (For those reading this blog post, some of Jeremy's accomplishments are listed on his website).

Without having a way to communicate, Jeremy would never have been able to tell us about his gift of synesthesia, and we would not have been able to encourage him to follow this path as a career. As you know, the unemployment rate for autistic adults is very high. We are grateful that we found out he has a gift that can help him be productive.

If ASHA's mission is "Making effective communication, a human right, accessible and achievable for all," then why are some in ASHA suggesting withdrawing a system of communication that is obviously effective for some people? Clearly more research is needed. But if finalized, the proposed statements would severely restrict ASHA members' discretion and ability to exercise professional judgment. It would also and would make ASHA's assertions about wanting to respect "client preferences and values" untrue.

I hope that ASHA does the right thing and upholds the human rights of all, including those who communicate in the manner that my son does.

Sincerely and respectfully,

Chantal Sicile-Kira

June 23, 2018

"The Gang"

https://www.facebook.com/S2CInsideVoice/posts/409770709505818

"The Gang Writes an Open Letter to ASHA"

Dear ASHA,

We are a group of young adult non-speaking autistics from the Philadelphia area, known as "The Gang." We use a letterboard to communicate. Please accept our comments below in regards to your drafted Position Statement concerning RPM and FC:

G: My name is Gregory and my life was forever changed by a letterboard.

A: My name is Alex and a year ago I was freed from silence when I picked up a letterboard.

N: My name is Nasser and I use a letterboard to communicate.

K: I am Kevin and I have autism and spelling to communicate has made me finally have a voice.

S: My name is Sarah I have autism and I am communicating with you today via letterboard.

B: I am Brian and I am an autistic adult who communicates by spelling my thoughts.

G: For years I went to countless therapies and doctors who all believed the issue was my brain. Well guess what? They were wrong. No one ever assumed the problem was with other people's presumptions about my abilities.

A: I have tried every therapy and doctor imaginable. Until this year I sat in a classroom learning about preschool level content. For the first time in my life I am feeding my brain with content to make it grow, all because of Letterboard.

N: Want to know what therapies I've tried? You name it, I've tried it. Until spelling to communicate, everyone said my brain was the problem. Why is that? Because I assure you that is not the case.

K: I'm going to be blunt about this. No therapy has worked as well as S2C. That includes evidence based therapies. Those supposed therapies treated me like I was an idiot. S2C has never once presumed I am incapable.

S: I have been through every practice you can imagine. None have yielded the results of S2C. This therapy is life changing. It has given me the opportunity to participate in life rather than be a bystander.

B: Think of every therapy. I have been through it. None have come close to S2C. I implore you to observe a session. You cannot unsee it.

G: For the first time in my life I have been able to make decisions for myself. Earlier this year I was able to use the letterboard to express myself during a medical scare. To say this is life changing is an understatement, it is life saving.

A: For the first time in my life I have a say. From what I want to eat, to how I dress, to my medications, I finally have a sense of control.

N: People take for granted their ability to make decisions. I finally have the ability to contribute my opinion on decisions about my life. That was also made possible by S2C.

K: Prior to spelling I lived a life of 24-7 stress. Think of the most stressed you have ever been. That was my daily life. Spelling helped open the door to express my struggles.

S: Prior to letterboard nobody thought I could be capable of intellectual thoughts. Now people talk to me like I am a functioning adult. My family dynamic has changed for the better. I am closer to them than ever.

B: Since starting S2C I have a new perspective on life. I can talk to my loved ones. I can tell my brother to stop being an idiot. My language is now more expressive. I can now make more decisions regarding my life. I can also flex my pristine wit and sense of humor.

G: You would rob me of the ability to play an active role in my own life, if you do not open your minds to this method of communication. I am not only speaking for myself, but non speakers everywhere.

A: The consequences regarding this decision are huge. I am talking restricting education to just neurotypicals. That is not what makes our nation great. We are a country that was founded on ideals that ideas are to be discussed not rejected just because they are different. This decision contradicts that ideal.

N: This would rob me of a full education. I have a hunger to learn. Keeping me in special ed classes will only hinder my potential. That shouldn't be the goal of the education system.

K: This decision does not affect me but it does have an affect on my friends. That I cannot idly sit by and watch. I ask you to reconsider your stance.

S: I need this method. It has allowed me to build friendships and communicate with my loved ones, don’t take this away from me.

B: I have spent the majority of my life in silence and I don’t want that to be the case for anyone else moving forward. There are communities across the country similar to ours here in Philadelphia who want to make this change to prevent future non speakers from spending their life in silence.

Sincerely,

The Gang

June 22, 2018

Rachel Maeroff

natcontherapy@gmail.com

To the Board of Directors,

I am writing to you in response to the Proposed Position Statement on FC and RPM. My name is Rachel Maeroff. I have been working with autistic children on and off for almost 20 years. I started a behavioral therapist with children under 3. I then certified as a BCABA and spent 5 years developing and managing programs for early intervention. I also consulted and worked with a number of older children. Here are a few of my observations:

After early childhood, much of ABA programming appeared inappropriate. The children who were still receiving ABA services had not shown mastery of basic concepts and activities. Instead of trying a new approach, or trying more challenging material, it was repeated. For years.

While ABA can teach vocabulary and some discrete skills, there is nothing inherent in ABA that supports LANGUAGE development, or deep communication.

Most ABA practitioners ignored sensory needs and issues with motor control; all actions (or lack thereof) are attributed to mental deficiency or lack of motivation. Research on motor complications runs counter to this approach (see below).

Children who were challenged with more advanced materials, and children who were allowed to stim and take breaks upon request, progressed further than those who did not have that type of programming.

Children with verbal skills and better motor control were treated as more intelligent and capable than those who were non-speaking.

Compliance is often valued over connection and understanding.

I left the field of ABA because the concept of mind/body disconnect was impossible to fathom by most of my colleagues. I left because ABA, despite being the evidence-based gold standard treatment, is generally shallow, leaves many children stuck for years on end, and self reports from adult autistics discuss how dehumanizing the therapy was for them.

The field of research is far from pristine. Bias in research is common1. Standards of practice change regularly. Top studies are overturned years later when conflict of interest, bias, or methodological errors come out. In the field of therapy, most approaches start outside of the lab. They start in day to day practice. People trying something new, and depending on how it goes, eventually it moves on to be studied in research. So until there is a body of well-conducted research, it seems short-sighted to label a new approach inappropriate.

In regards to the proposed position statement on Facilitated Communication and Rapid Prompting Method, there are a few things that I would like to highlight:

In lines 58 - 63 the authors state, “Both RPM and FC are facilitator-dependent techniques (i.e., techniques that involve the person with the disability being dependent upon a “facilitator” to compose a message)....in RPM the aide typically does not physically guide the hands of the individual but, rather, holds the letter board and provides ongoing repeated verbal and gestural prompts.”

Lines 94 - 96, “The role of the “facilitator” in the construction of messages delivered by RPM is to control the communication board and to confirm any “messages” delivered. Therefore, it is not possible to rule out facilitator influence over messages delivered using RPM.”

ASHA’s website, in relation to its discussion of appropriate use of AAC, outlines the role a communication partner may play with individuals using AAC, many of which are similar, if not identical to the roles a communication partner may take with RPM or FC. 2

Partner-assisted scanning is an indirect selection technique in which the communication partner presents messages or letter choices in a sequential fashion (visually or auditorily) to the individual, and the individual then makes his or her selection using a previously agreed upon motor act (blinking, grunting, raising a hand, etc.).

Strategic competence is the ability to use available features to convey messages efficiently and effectively, including

> asking for choices due to vocabulary limitations;
>
> using word/phrase prediction to enhance efficiency;
>
> using an introductory (pre-recorded) statement to explain AAC to unfamiliar communication partners; and
>
> asking one's communication partner to write or type messages to aid in understanding and to repair communication breakdowns

In addition to limitations of the AAC device itself and insufficient involvement in device selection, inadequate training of communication partners has been identified as a barrier to device use (Bailey et al., 2006). For example, when communicating with children who use AAC, communication partners are more likely to ask yes–no questions instead of open-ended questions, dominate the conversation, or fail to respond to the individual's communication attempts (e.g., Houghton, Bronicki, & Guess, 1987; Light, Collier, & Parnes, 1985).

The proposed position statement ignores the fact that RPM users have a goal of independent typing and communication. ABA, traditional speech therapy, and teaching in general, rely on prompts to teach new skills. Prompts can be verbal, gestural, or physical (hand over hand). These are all prompts used in teaching use of AAC to individuals without independent communication. Again, ASHA states in regards to AAC 2:

Visual prompting strategies use visual cues (e.g., pointing or gesturing) to help individuals with disabilities maintain attention, understand spoken language, sequence events, organize environments, or increase independence with task completion (Hodgdon, 1995). Visual prompts can be general (e.g., gesturing toward the communication system) or specific (e.g., pointing to a specific display location).

Picture Exchange Communication System (PECS) is a specific, manualized intervention program for individuals with ASD and other developmental disabilities that is intended to shape a child's expressive communication abilities using prompting and reinforcement strategies.

The authors erroneously conclude that RPM facilitators PREFER prompt dependency based on a statement that, "“Prompt dependency is preferred to the alternative of allowing no response or no learning to occur” (table 1). The quoted material is not saying that prompt dependency is ideal, but indicating that prompting is better than nothing. And again, this ignores the frequency of prompt usage AND prompt dependency is many therapies aimed at remediating complications of autism. 5, 6, 7

The authors of the proposed position statement also speak against presumed competence, referring to it as a “generalized philosophy” which ignores a growing body of research indicating complex sensory-motor involvements in those with autism. The possibility of these issues to impair testing for understanding and competency must be considered. 3, 4

Years after leaving the field of ABA I met families who had started using RPM. At first I was skeptical, but as I watched the students’ skills improve, and independence increase, it became clear they had found an approach that worked for a population of autistics often left behind by other therapies. I’ve watched many students spell with no prompting beyond an occasional bit of encouragement to continue. I’ve watched students who started on letterboards type independently on a keyboard, answering open-ended questions. Should I dismiss all of this? That doesn’t seem right. It doesn’t fit with ASHA’s mission to help everyone access communication.

I am now a private educator who works with autistic individuals to learn the motor skills to spell on a letterboard. I’ve seen children who are non-responsive or minimally responsive to other approaches, yet actively engage with age appropriate materials and respond to requests to spell, or to choose an answer from a set of written options. I see the increase in independence, engagement in skills. I see the development of skills that can lead to deep, independent communication, far more than I ever found possible in almost 7 years of ABA.

If this position statement is accepted and put forth as an official stance, ASHA runs the risk of withholding a valuable communication approach from many autistic individuals. Individuals who have progressed from the early stages of heavily prompted RPM to a place of independent typing. Individuals whose families, teachers, and communities have started to include in daily, mainstream activities, due to their newfound communication access. I encourage members of ASHA to reject this proposed statement. Spend some time reviewing the current state of people using spelling to communicate. Support research initiatives instead of shutting down a potential path to communication and inclusion for people who have been left behind by other current therapies.

Thank you,

Rachel Maeroff
Autism Educator

1 BMJ 2011; 342 doi: https://doi.org/10.1136/bmj.c7153

2 https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589942773&section=Key_Issues

3 https://www.frontiersin.org/articles/10.3389/fneur.2016.00124/full

4 https://www.ncbi.nlm.nih.gov/pubmed/26335740

5 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4711754/

6 https://nsuworks.nova.edu/fse_etd/29/

7 http://praacticalaac.org/praactical/reducing-prompt-dependence-in-aac-learners-5-things-to-try/

June 22, 2018

[REDACTED]

Hello,
I am a parent of a child that utilizes the RPM method to communicate his thoughts as he is an unreliable speaker. RPM has been extremely successful in allowing him to demonstrate his educational ability and higher level thinking. My son's speech is frequently in "scripts" and repetitive talk about subjects that he is interested in. For instance, if you were to ask him to answer a question about math/history/science lesson you just taught, he would either be silent, talk about a preferred subject or say "I don't know". However, if you ask him the same question using the RPM letterboards right after, he WILL spell out the correct answer. Without RPM, I would not have even known that my son even knows how to read, let alone spell out complex answers. One time, he spelled out on the letterboards that he learned to read at age 2—I would have NEVER known that!

If he is not allowed access to this preferred communication method, he will have great difficulty demonstrating his intelligence, attention and wealth of knowledge that he has gained over his life. I am a concerned parent that is disappointed that the Ad Hoc Committee has refused to get the input/evidence of the ones of the front-lines of RPM (ASHA members, RPM users and their families, teachers and practitioners who utilize RPM). Decisions should not be made lightly and should not be biased, but rather gather information from those on both sides of the issue prior to making a recommendation and ultimate decision.

I also find it highly disturbing that your organization states they desire to respect client preferences and values (motto “Making effective communication, a human right, accessible and achievable for all”) while simultaneously attempting to remove this preferred method as a choice and dismiss individuals who prefer this method. In order to remedy this situation, I propose the following: 1) Withdraw the proposed position statements 2) Issue a formal apology for the damage that has already been done to the civil rights of individuals with disabilities by the Ad Hoc Committee.

Thank you for your attention to this matter

June 23, 2018

David Krause

dkrause@zcs.k12.in.us

To Whom It May Concern,

We are very disappointed and gravely concerned with the ASHA’s Ad Hoc Committee on Facilitated Communication and Rapid Prompting Method’s recent Draft Position Statements on these forms of communication. Not only have these methods been in use for many years, but it should be the ASHA’s mission to increase the choices available to their members so that professional judgement and client’s wishes determine the best course of action in a given situation. While there may have been some instances in the past involving the misuse of FC and RPM, our daughter would not have achieved the successes she has without the aid of FC.

We are the parents of a non-verbal child who is on the spectrum. For the first 16 years of her life she was not able to express her thoughts to us other than by pointing and/or making guttural sounds. We tried more methods than we care to remember in an attempt to get her to communicate. We despaired that she was doomed to the “life skills” classes at her school, until we came across FC. When introduced to FC our daughter blossomed. She was taken out of the life skills classes and placed on a diploma tract. She had her own column in the school newspaper and just graduated with a 3.933 GPA. This success story of our daughter, and probably many others like her, would not have happened were FC not an option available to her.

The Position Statement uses terminology indicating the FC is “discredited” and is merely the voice of the facilitator. We wholeheartedly disagree. By way of some background information, during the time before our daughter was introduced to FC, I taught biology at a local college. I was always leaving textbooks and examinations laying around. Our daughter would pick these up and appear to be reading them. We thought she was just looking at the pictures. After FC we quizzed her on some of the information that she may have picked up. She was able to answer my questions correctly. This could not have been the facilitator responding due to lack of subject matter knowledge.

Fortunately, our daughter is able to enjoy the benefits of FC. We shudder to think of all the other children whose lives will be devastated by missing out on this opportunity if the ASHA adopts the Ad Hoc Committee's position on FC. Please do not take away this valuable tool that has the potential to help hundreds of thousands of children. The decision on whether or not to use FC should be left up to the practitioner's professional judgement and the wishes of the client.

Thank you for allowing us to share our story.

David and Angela Krause

June 23, 2018

Sara Al-Hadithi

saraalhadithi@gmail.com

My name is Sara Al-Hadithi. I am the mother of a 12-year-old nonverbal young man who is on the autism spectrum. He has been using FC and RPM for four years as part of his access to communication tools. Along with basic ASL, we have found this to be the most positive experience for my son in him expressing himself, showing us various levels of understanding and comprehension and reinforcing his self-confidence.

For many years, my son had been receiving speech therapy, which was repetitive and failed to challenge his intellectual ability appropriately. This resulted in various avoidance and attention-seeking behaviors, reducing an hour's session to maybe 15 minutes of work. During this time he was also receiving ABA therapy, which failed spectacularly. Along with speech therapy techniques that did not show any progression on his part that elevated behaviors from him, there was also the introduction of programs like Proloquo2go that, although they are extensive and vision-based, and easy for my son to navigate, still limited what he would be able to say or express because his options were all chosen for him. To conclude, the program was still limited and not spontaneous, as my son would have to go and find his iPad and then scroll through Proloquo for answers that have already been provided.

Since the introduction of FC and RPM, from the first session, my son's behaviors decreased dramatically. The methods and techniques that are used to keep a child engaged, as well as to obtain what the child has understood from the session, have been far more successful than any speech or behavioral sessions that my son has attended previously or since. The reasons for this being, more age-appropriate material and subjects were covered in a manner that was accessible to my son's development and respectful of his age and intelligence rather than the previous methods that did not differentiate between a 2-3-year-old and an 8-9-year-old. In conclusion, my son has looked forward to his sessions. He has consistently worked for periods of an hour with little or no breaks, he has been able to self-regulate during sessions and this is all due to the

increase in his confidence after being given a method to communicate his thoughts.
I am concerned that if my son would no longer have access to this preferred communication method, I am almost certain he will not only regress in his interactions with people, but I am convinced that his behaviors will increase through the frustration of not being able to express himself via, what has clearly become, a method of HIS choice. Further, I am extremely concerned at the current course of action by the ASHA committee when I have learnt that they have not only failed to consult users and members who have experience with these methodologies but have refused to consider input and evidence from users and members. I think it is crucial that a policy decision that is of this magnitude should absolutely involve unbiased examinations of viewpoints rather than a committee of individuals who have a very worrisome history of attacking and insulting these two methodologies. More disgracefully, they have made disparaging remarks about individuals with disabilities who use and rely on these methodologies. I believe that decision makers at ASHA have a great opportunity here to repair the damage that has been done to the civil rights of the individuals with disabilities by this ad hoc committee by issuing a formal apology and showing that the ASHA respects and listens to the voices of those who rely on these methods. FC and RPM have allowed many, like my son, to enjoy being able to participate as part of this world by showing their abilities rather than being denied that right because of their disability. I sincerely hope that ASHA will do the right thing by withdrawing these proposed statements immediately.

Kind regards

Sara Al-Hadithi

June 23, 2018

Ian Aronow
[REDACTED]

To the Members of ASHA:

I am writing to you with regard to the recent proposed position statement certain committee members have generated toward RPM.

Although this committee has recommended against the use of RPM and stated that any communication made through spelling with this method is suspect, I ask that you read my letter anyway. You see, I am a nonspeaking 16-year old autistic guy using a letter board to write to you now. I am spelling my thoughts. I am pointing to the letters. No one is moving my hand or the board. No one is telling me what to spell. My mom is holding the board. This helps me stay focused. It is hard for me to hold the board myself when I spell, but I am making progress with this goal. I am also working on typing independently. Speaking each word after I spell them is also a skill I work on. I am telling you all of this to let you know that I want full independence with my communication. But that I need RPM to help me get there. Will you take my words seriously, even though you have been told not to? Can you give me the benefit of the doubt? Feel my awesome plea with real, open minds.

Recently, at an appointment with my developmental pediatrician I got to demonstrate my spelling to communicate. It felt awesome to have a conversation with the doctor. We were worried he might think like the committee and just dismiss the process. So, it was a relief that he took the time to observe me spell. He asked me personal questions and I could give him in-depth answers. He did not doubt that I was communicating under my own power. He understood that any support (like a prompt or my mom holding the board) is sometimes needed due to what he has diagnosed as my “severe motor dyspraxia.” I was on fire that day though and didn’t need any prompts.

I get that some of you fear that these prompts and the support we sometimes need means we are being manipulated like puppets. This concern has you turning your backs on real human potential.

I think no matter what ASHA decides, I will continue the journey to fully independent communication with great success, but I would love the chance to have you on my side. This is difficult to do when you know there are others who think you are permanently disabled. Talk to us and try to see our gifts. You are so focused on the so-called methods that you are missing the people that you have pledged to help.

Thank you for your time. I hope you will consider NOT adopting this position on RPM. I feel that such a position will hurt many in the nonspeaking autistic and disabled community.

Sincerely,

Ian Aronow

June 23, 2018

Pauline Gaivin
PO Box 2257

Yelm, WA 98597

gg5boys@hotmail.com

American Speech-Language-Hearing Association
Attn: Board of Directors
2200 Research Boulevard
Rockville, MD 20850-3289

Re: My grandson Evan and the proposed ASHA position statement on FC/RPM

To whom it may concern:

I am writing this letter as a grandmother of 5 boys whom I am so very proud of and love with all my heart. Each one is unique and special to me but today I want to introduce you to Evan my soon to be 15 year old grandson.

Evan is autistic and was diagnosed at 22 months. He is non speaking due to severe apraxia. Over the years I have watched as he received speech therapy several times a week. Again I watched as he was introduced to PECS . Then it was a voice output communication device. I watched him as he used gestures in attempts to communicate. Often he would tug at my shirt and look at me with those big blue eyes desperately trying to tell me something. I would try and guess what he wanted but often failed and then I would see the saddest look on his face. It would break my heart.

Then a miracle happened. My daughter learned about RPM and Evan started using a letter board. After all these years Evan was finally able to communicate.

A few weeks before his 14th birthday my daughter sent an email to all the relatives and told them they could send her any questions they may have and she would ask Evan to answer them. Luckily for me I was visiting California at the time and sat there as my daughter read Evan each question and told him who was asking. Two questions in particular and his answers totally overwhelmed me.

Question #1: If I were to tell a friend about you, what would you want them to know?

Answer: I would want them to know that I am definitely smart and that all these motor tics around my body allow me to use up energy. I am a very magical boy with incredible powers to hear everything. Talking isn’t in my repertoire but I love to spell to communicate my thoughts.

Question #2: You are so smart Evan. How have you been patient in school when at times teachers aren’t challenging you?

Answer: I would feel some level of understanding because I couldn’t respond.

Now because of his letter board he has been able to communicate. He was tested repeatedly at school and proved to be gifted in many areas. His teachers were amazed. Spelling to communicate gave him his voice.

This has been an incredible journey not only for Evan but also for his family, teachers, and all who love him. As a grandmother you want your grandchildren to love you but you can never be100% sure. For years I would look into Evan’s big blue eyes, tell him I loved him, and get nothing in return. I will be eternally grateful for spelling to communicate because one day Evan typed out “I love you”.

I hope I was successful in introducing you to Evan. After many years spelling to communicate introduced him to me. I learned Evan has a fantastic sense of humor, he can be quite poetic, and he has tremendous compassion and that his Mom is his superhero. I never would have known these things if it weren’t for the letter board.

Please, I beg you, please withdraw your proposed statements. If Evan is prevented from using his letter board as his communication method you would be taking away his voice.

Thank you for your time.

Sincerely,

Pauline Gaivin

June 24, 2018

Evelyn Moldal

evelyn.moldal@gmail.com

Dear ASHA Board of Directors:

My name is Evelyn Moldal. I am a school teacher. I have spent the last 18 years pursuing my passion in educating the youth in my community. Seeing their eyes light up when a concept has clicked, their quizzical expressions when they have encountered something new, their infectious smiles when they feel a sense of accomplishment and the community that is created within the classroom are a few examples of what fuels my passion.

Over the years, I have worked with students with diverse cultural backgrounds and varied learning profiles.The most unique challenge I have encountered so far has been working with students with severe communication challenges. Together with other professionals (Speech and Language Therapists, Occupational Therapist, Behavior Therapists) we incorporated various methods of communication into the classroom setting with the goal of discovering what would work best for each individual. Those methods included, but are not limited to sign language, PECS and ProLoQuo. These methods were limiting and difficult for my students. Although they were able to use them to get their basic needs met, it didn't help with participation and inclusion in curriculum.

It wasn't until my students and I started using spelling as a means of communication that I was able to *clearly* see what they were capable of. For example, when we taught a unit on Thailand one lesson focused on the language. One lesson in particular taught the students how to say, write and read numbers in Thai. At the end of the lesson, the students were asked to write their birthday in number form in Thai. The three students I worked with as their communication partner for that lesson were able to successfully communicate (through spelling on a letter board) their birthday in Thai without referring to the Thai number translation on the board. The Thai language (as do most foreign languages) has specific rules governing how to properly express numbers that make learning and expressing larger numbers tricky. Before we had the students perform this task, the teachers were instructed to write their birthdays first. I can tell you, this was not an easy task for the other teachers or me. It took referring to the board many times and conferring with the other teachers to be able to successfully write my birthday in the Thai language in number form. I know that if my students had to write or speak their answer to this specific question not one of them would have been able to do it. So my assessment of whether or not they understood the content presented would have been 100% inaccurate if I was relying on traditional methods of communication. Another one of my students was able to tell me, through spelling on a letter board, that she needed help during the school day in order to maintain regulation. She then proceeded to tell me (by spelling on a letter board) exactly what to do to support her. These are just two examples of recent experiences with my students. There are so many wonderful things happening with my students on a daily basis that I could write a novel with examples! For my students and others like them, their limited speech (if any at all) and body language paint an entirely different picture than what is going on cognitively. If we had stuck with PECS/ProLoQuo we would not have been privy to all this information they so desperately wanted to share. I can't even begin to imagine the frustration my students had been feeling as a result of such limited and unreliable communication before learning how to spell to communicate!

In addition, learning the motor control necessary to point to letters has helped to increase their *overall* motor control allowing for meaningful participation in their school, family, and community. They can ask questions, tell stories, express desires. Their parents have told me, often through tears of joy, how exhilarating and exciting it has been for them as they are finally getting to know their own child.

I cannot imagine that an association such as ASHA, whose very slogan is "Making effective communication, a human right, accessible and achievable for all" would seek to discredit and remove access to a form of communication that is working for so many. I implore you to refer to your own definition of EBP and withdraw the proposed statements. A formal apology needs to be issued for the damage that has already been done to the civil rights of individuals with disabilities by the Ad Hoc Committee. Do the research, talk to the practitioners, clients and their families.

Respectfully, Evelyn Moldal

Cc: ASHA Board of Ethics, Heather Bupp, Esq. ASHA Governance, Marty Moor

---

June 23, 2018

[REDACTED]

I respectfully ask that ASHA choose a new committee and reverse its draft position statement regarding the use of two methodologies, Facilitated Communication and Rapid Prompting Method.

Clearly, a respected organization such as yours must not allow your Ad Hoc Committee to make policy that clearly violates the civil rights of individuals with disabilities. Why did the committee refuse to consider input/evidence from users of these methods or from ASHA members with experience in the use of them? I personally am not surprised that the American Psychological Association erred similarly, given their history of blaming autism on “refrigerator mothering.” And please remember the history of American Sign Language. It was banned from being taught in most schools for decades. I feel sure an organization with your status would hesitate to make a similar and embarrassing mistake.

At least two members of the Ad Hoc committee published research that was negative and were active and highly vocal opponents, publicly criticizing the method for many years and accepting fees for negative testimony in court. How could you include members who came in with such a tremendous bias? It’s highly unethical on ASHA’s part, and the public will likely not stand for it.

As with any method of communication, caution, common sense and the use of best practices is important.

I am mother of a daughter with autism. We tried every known means of communication, with little to no success before using Facilitated Communication. And we are still open to the use of every means. Granted, it is not a perfect method, but neither is speech, writing, signing, etc., nor is influence absent from any. We are careful. For example, when an important choice is requested, my daughter is asked for an entire sentence rather than a yes/no, or even a phrase, to ensure there is no misinterpretation of her intent.

Please consider what my daughter writes:

I was born when typing happened. Alive, with words churning out of a dumb body. I loved and hated, was happy and sad, and lots scared--and now I could tell these feelings. I said wishes, and they often came. When I was silent the wishes were not coming. I became a good student and a poet and a tattletale. I voted for high hopes and read books and chose restaurants. People listened with their eyes and answered my big, new voice. With typing, I became a real person.

With just a touch on my arm I felt connected to my hands and could move them where I wanted. Without a touch, my body did what it pleased, and didn't listen to me.

When my daughter had success with this method about 25 years ago, we immediately did informal blind message passing to ensure it was valid. Later, Dr. Don Cardinal (Professor at Chapman University and recipient of the prestigious Wang Fellowship for exemplary research) did a study using the protocol of the 1960’s determination that one person wrote all the works of Shakespeare and to determine the author of the Federalist Papers. He studied common usage and stylistic idiosyncrasies of thousands of my daughter’s words across four different facilitators and determined they were of the same author. Another blind message study proved she was communicating. Her communication method was studied under guidelines that were set forth by ASHA at the time, and F.C. was approved for her classroom use by the BOE Augmentative Communications Team. And, when she took the State Assessment tests necessary for graduating, a State official sat across from her, watching closely. This scrutiny was welcome. She took the test with either a light touch on her shoulder or, for two or three questions at a time, no touch at all.

Please read what psychologist William A. Sherman, Ph.D. observed in his Evaluation when my daughter was transitioning from high school. He was considered an expert in communication who was specially chosen by DORS to do an evaluation and recommend.

"Related to any controversy about [her] use of facilitation, it was clear in testing that [Ms. ___'s] contact was entirely prompting, not influencing It is more realistic to describe [Ms. ___'s] role as that of reducing Sarah's inner distractions. She is more of a stimulus reduction agent than a facilitator. Sarah's distractions are largely internal, so [Ms. ___] redirects her from the nonproductive, repetitive movements or behaviors. Sarah's rapport with [Ms. ___] was obviously comfortable. She did not react to [Ms. ___'s] interventions as intrusive. She did shift the irrelevant behaviors to socially acceptable ones, such as increased eye contact and pertinent responding through the Canon, in response to [Ms. ___'s] cues. [Ms. ___'s] touching of Sarah's arm to prompt her typing could not have been directive, as there was no influential force exerted and the position of [Ms. ___'s] hold could not subtly guide Sarah's one finger typing. The physical touch is enough to keep Sarah on task, so that she can output her inner thoughts through electronic means. The rate of Sarah's responding denied any possible direction from [Ms. ___]."

Please direct a new, unbiased committee to observe F.C. and RPM users. Surely, after reading the above, you'd agree that it's absolutely essential.

Investigate how some of the blind message testing in some of those cited in the Policy Statement were conducted. I know that the majority of participants in some were not candidates for using the method and had never been introduced to the method or practiced prior to the testing, nor were their facilitators well trained or experienced. Further, we all know that those with autism cannot function as well when they are in a new environment with new people. Few studies accommodated for this, and those that did were not even included by your committee.

Note that professional proponents are in favor of inclusion and that opponents are not. (They are adversaries on other fronts.)

"Harm" caused by use of the method includes reporting of abuse, per your position statement. Why would the reporting of abuse be considered "harm?" Imagine! Stopping nonverbal people with disabilities from reporting abuse? Who would risk, or feel they had the right, to prevent them? What kind of person or organization? Only the local law enforcement is responsible. Any "harm" is due to poor law enforcement practices and <u>not</u> your responsibility. The second "harm" mentioned is that people with disabilities wouldn't be exposed to other ways of communicating. I feel certain virtually all of them have tried all available methods before using F.C. and/or RPM, and I also feel sure they will continue to try many methods. How can you assume otherwise without checking with schools and families? It's somewhat insulting to assume this, is it not?

Also please note that the accusations of sexual misconduct from F.C. users have sometimes resulted in arrests of innocent people. Proper handling of these accusations would have checked the communication and ability of the facilitator as well as some questioning of others <u>before</u>

arrests were made. Why is it that the public blames the method rather than poor police work? And why is it that it would surprise anyone that accusations would come out since nonverbal people are particularly vulnerable to abuses of any kind, and the statistics show that people with intellectual disabilities are sexually assaulted at a rate seven times higher than those without disabilities according to data run for NPR by the Justice Department from unpublished federal crime data.

Yes, we all need to be cautious with this method until we know more about it. We'll never learn if we are afraid of scrutiny and progress. Your position statement will prevent the freedom and flow of research needed to learn more about why and when it works and why it sometimes cannot be easily demonstrated. Your former policy statement did include precautions. But this new one is nothing short of a violation of civil rights.

Carefully guard the respect your organization has earned. Carefully select a new, unbiased committee that will sit down with communicators and with schools and families and will be open to all research and to full inclusion.

Thank you for the opportunity you have given us to comment freely. As my daughter has typed, "Listen in a new way."

[REDACTED]

June 23, 2018

Jan Goldsmith
goldjan55@hotmail.com

The Board of Directors
ASHA

Attention: Ad Hoc Committees on FC and RPM

Dear Committee Members

I am a mother of an autistic man of 34 years. At the age of 22 years and non-verbal, he was introduced to Facilitated Communication (FC).

To say this was life-changing is an understatement. At that time, he was attending Day Services for people with disability. As a non-verbal member of the group his needs weren't easy to identify and he spent his days on a bus doing "activities" that didn't interest him but did interest the majority of members of the group. This led to extreme frustration for him.

He had tried other communication methods at his special school, none of which met his needs. He was considered intellectually impaired all through his school years as he didn't have access to a form of communication to indicate his needs or thoughts.

When we met his future Speech Pathologist who did an assessment of him in 2005, he immediately could use FC and we realized he was literate and intelligent. He could now tell his family that he was frustrated with his life and needed more. We began to self-manage his funding and he has moved into a house with a regular house-mate at night and support workers and family members supporting him during the day. He has a small mowing run, belongs to two writers' groups (one for FC users and one mainstream) has just written a song which is being put to music by his friends in an Arts group run for people with disability. With support he maintains his home and lawn, shops and participates in community life.

Working closely with his Speech Pathologist, he is now increasing his verbal speech and he is now working with a Music Therapist who is also seeing improvements in his vocal abilities.

If my son wasn't able to access his chosen form of communication, he would still be that boy sitting in the back of the "special bus" doing "activities" with the group. He is now a home owner, worker, singer and writer. He mows lawns, cycles and attends the gym. He votes in all elections and participates in all decisions impacting all aspects of his life. He hosts a monthly coffee morning at his home for his friends who also use FC and they relish the opportunity to share their dreams and problems as any other group of friends would.

It's distressing to families and FC users of many years to think ASHA's Ad Hoc Committee doesn't consider input from the people who have benefited from the access to their own chosen form of communication. The thought of other potential users not accessing or even knowing about FC is terrible.

My son has added his own thoughts on this issue and I attach this to the email as well.

Sincerely,

Jan Goldsmith (Parent of David) Brisbane, Australia.

June 23, 2018

Jason Morris

jasonmo17@hotmail.com

I am writing this letter in response to ASHA's statements on facilitated communication.

I am the mother of a non-speaking autistic 14 year old son. My son had an early diagnosis at 21 months, and we began ABA and speech therapy immediately. We worked hard with many therapists for almost 4 years with very little improvement in any of the areas that we were focusing on. His behaviours started to become much more pronounced at 4 years old. We continued on and tried using our “evidence” based approach for another year until finally we decided that we had to try something different for my son as ABA was not effective.

The next program we began for our son was the Son-Rise program. This is also a program that has been dismissed by the powers that be as unscientific and not evidence based. My son made notable gains with this program over the next few years. He toilet trained within the first month of the program, regained spontaneous eye contact, and engaged with individuals and family members again. These are all goals that were not reached with years of “evidence” based therapies. Unfortunately, as my son grew he struggled with self injurious and “aggressive” behaviours along with the inability to sit still at a table for any length of time. He outgrew this program, and we felt that he needed something more in order to reach a deeper level of communication that would give him a more meaningful way to interact in the world and gain more control over his body. We wanted to give him the best chance we could to help him reach his highest potential.

We went searching and found spelling to communicate. In the last 2 years since starting spelling to communicate my son went from spending much of his time tormented by a body that he simply could not control. Once we began working from the premise that my son understood what we were saying but was suffering from dyspraxia his life was forever changed. We understood that a language deficit wasn’t the problem; the problem was a motor challenge. The inability for his brain to work symbiotically with his body.

The more time we put into focusing on his motor challenges the easier my son’s life became. He recently attended his first group trip to a farm that he was able to enjoy and engage with. In the past he would have appeared overwhelmed and would have had to leave immediately. His self-injurious behaviour is a rare occurrence now.

Our son has recently been able to take part in an online course on anatomy and physiology with fellow spellers. He has the opportunity to connect with fellow autistic friends who use spelling to communicate and was able to sit at a table for the duration of the class. He participated on a special needs hockey team this past year wearing full equipment. Something I never could have imagined him doing as even wearing clothes were a challenge for him. He was able to take horseback riding lessons because he could control himself enough to wear a helmet. Again something that I would never have attempted in years past. Most importantly his self harming and “aggressive” behaviours are a rare occurrence. His days that were once filled with so much strife and pain are no more. He enjoys learning and being a part of the world instead of living on the sidelines. Prior to spelling this was often his only option.

I understand varying viewpoints, and I understand that when one lives within the walls of a certain paradigm, it is hard to comprehend any other possibilities. However, I cannot understand seeing a modality change the lives of so many in ways so far reaching, going beyond mere words and trying to disable it for such individuals. I cannot understand taking away human rights for individuals that have had a lifetime of pain already. Taking away hope for families and taking away the genius that these autistic individuals can bring to the world. With the statement that ASHA has put forward this is exactly what is happening. This isn’t about whether or not the communication from autistic individuals using FC or RPM is autonomous or not. Whether or not you choose to see what is obviously true doesn't matter. The evidence of this communication modality changing autistics' lives is not up for debate. The statement made by ASHA is a human rights violation against autistics and spellers everywhere without any true scientific knowledge to back up such a huge and harmful declaration. If you are calling for evidence to support, then we call for evidence to dispute, and you have not provided any such thing. I ask for this statement to be withdrawn and a formal apology to be offered to all individuals who use facilitated communication.

Thank you!

June 23, 2018

[REDACTED]

I respectfully ask that ASHA choose a new committee and reverse its draft position statement regarding the use of two methodologies, Facilitated Communication and Rapid Prompting Method.

Clearly, a respected organization such as yours must not allow your Ad Hoc Committee to make policy that clearly violates the civil rights of individuals with disabilities. Why did the committee refuse to consider input/evidence from users of these methods or from ASHA members with experience in the use of them? I personally am not surprised that the American Psychological Association erred similarly, given their history of blaming autism on "refrigerator mothering." And please remember the history of American Sign Language. It was banned from being taught in most schools for decades. I feel sure an organization with your status would hesitate to make a similar and embarrassing mistake.

At least two members of the Ad Hoc committee published research that was negative and were active and highly vocal opponents, publicly criticizing the method for many years and accepting fees for negative testimony in court. How could you include members who came in with such a tremendous bias? It's highly unethical on ASHA's part, and the public will likely not stand for it.

As with any method of communication, caution, common sense and the use of best practices is important.

I am mother of a daughter with autism. We tried every known means of communication, with little to no success before using Facilitated Communication. And we are still open to the use of every means. Granted, it is not a perfect method, but neither is speech, writing, signing, etc., nor is influence absent from any. We are careful. For example, when an important choice is requested, my daughter is asked for an entire sentence rather than a yes/no, or even a phrase, to ensure there is no misinterpretation of her intent.

Please consider what my daughter writes:

I was born when typing happened. Alive, with words churning out of a dumb body. I loved and hated, was happy and sad, and lots scared--and now I could tell these feelings. I said wishes, and they often came. When I was silent the wishes were not coming. I became a good student and a poet and a tattletale. I voted for high hopes and read books and chose restaurants. People listened with their eyes and answered my big, new voice. With typing, I became a real person.

With just a touch on my arm I felt connected to my hands and could move them where I wanted. Without a touch, my body did what it pleased, and didn't listen to me.

When my daughter had success with this method about 25 years ago, we immediately did informal blind message passing to ensure it was valid. Later, Dr. Don Cardinal (Professor at Chapman University and recipient of the prestigious Wang Fellowship for exemplary research) did a study using the protocol of the 1960's determination that one person wrote all the works of Shakespeare and to determine the author of the Federalist Papers. He studied common usage and stylistic idiosyncrasies of thousands of my daughter's words across four different facilitators and determined they were of the same author. Another blind message study proved she was communicating. Her communication method was studied under guidelines that were set forth by ASHA at the time, and F.C. was approved for her classroom use by the BOE Augmentative Communications Team. And, when she took the State Assessment tests necessary for graduating, a State official sat across from her, watching closely. This scrutiny was welcome. She took the test with either a light touch on her shoulder or, for two or three questions at a time, no touch at all.

Please read what psychologist William A. Sherman, Ph.D. observed in his Evaluation when my daughter was transitioning from high school. He was considered an expert in communication who was specially chosen by DORS to do an evaluation and recommend.

"Related to any controversy about [her] use of facilitation, it was clear in testing that [Ms. ___'s] contact was entirely prompting, not influencing It is more realistic to describe [Ms. ___'s] role as that of reducing Sarah's inner distractions. She is more of a stimulus reduction agent than a facilitator. Sarah's distractions are largely internal, so [Ms. ___] redirects her from the nonproductive, repetitive movements or behaviors. Sarah's rapport with [Ms. ___] was obviously comfortable. She did not react to [Ms. ___'s] interventions as intrusive. She did shift the irrelevant behaviors to socially acceptable ones, such as increased eye contact and pertinent responding through the Canon, in response to [Ms. ___'s] cues. [Ms. ___'s] touching of Sarah's arm to prompt her typing could not have been directive, as there was no influential force exerted and the position of [Ms. ___'s] hold could not subtly guide Sarah's one finger typing. The physical touch is enough to keep Sarah on task, so that she can output her inner thoughts through electronic means. The rate of Sarah's responding denied any possible direction from [Ms. ___]."

Please direct a new, unbiased committee to observe F.C. and RPM users. Surely, after reading the above, you'd agree that it's absolutely essential.

Investigate how some of the blind message testing in some of those cited in the Policy Statement were conducted. I know that the majority of participants in some were not candidates for using the method and had never been introduced to the method or practiced prior to the testing, nor were their facilitators well trained or experienced. Further, we all know that those with autism cannot function as well when they are in a new environment with new people. Few studies accommodated for this, and those that did were not even included by your committee.

Note that professional proponents are in favor of inclusion and that opponents are not. (They are adversaries on other fronts.)

“Harm” caused by use of the method includes reporting of abuse, per your position statement. Why would the reporting of abuse be considered “harm?” Imagine! Stopping nonverbal people with disabilities from reporting abuse? Who would risk, or feel they had the right, to prevent them? What kind of person or organization? Only the local law enforcement is responsible. Any “harm” is due to poor law enforcement practices and <u>not</u> your responsibility. The second “harm” mentioned is that people with disabilities wouldn’t be exposed to other ways of communicating. I feel certain virtually all of them have tried all available methods before using F.C. and/or RPM, and I also feel sure they will continue to try many methods. How can you assume otherwise without checking with schools and families? It’s somewhat insulting to assume this, is it not?

Also please note that the accusations of sexual misconduct from F.C. users have sometimes resulted in arrests of innocent people. Proper handling of these accusations would have checked the communication and ability of the facilitator as well as some questioning of others <u>before</u> arrests were made. Why is it that the public blames the method rather than poor police work? And why is it that it would surprise anyone that accusations would come out since nonverbal people are particularly vulnerable to abuses of any kind, and the statistics show that people with intellectual disabilities are sexually assaulted at a rate <u>seven times higher</u> than those without disabilities according to data run for NPR by the Justice Department from unpublished federal crime data.

Yes, we all need to be cautious with this method until we know more about it. We’ll never learn if we are afraid of scrutiny and progress. Your position statement will prevent the freedom and flow of research needed to learn more about why and when it works and why it sometimes cannot be easily demonstrated. Your former policy statement did include precautions. But this new one is nothing short of a violation of civil rights.

Carefully guard the respect your organization has earned. Carefully select a new, unbiased committee that will sit down with communicators and with schools and families and will be open to <u>all</u> research and to full inclusion.

Thank you for the opportunity you have given us to comment freely. As my daughter has typed, “Listen in a new way.”

[REDACTED]

June 24, 2018

Lori Pumpa

carol.thorne1@bigpond.com

My name is Lori and I am a trained facilitator of the facilitated communication practice. I am a support worker for a young man with cerebral palsy who can not speak and is wheel chair bound (this is relevant as he has a limited ability to express his needs by "showing" us, he must "tell" us if we are to exceed his base level needs) but he is also an incredibly intelligent, wickedly cheeky and caring individual.

I know thos because for the past several years we have been communicating effectively through FC. I am disheartened and somewhat angered on behalf of the individuals who rely on FC as their only accessible form of communication to hear of this proposed position your organisation has taken to FC.

Firstly I was disappointed by your definition of FC as it was not at all objective.

In your definition of FC the term "allegedly" appears which I found inappropriate as opinion has no place in a definition as it manipulates the readers thoughts.

Secondly I find it extremely ignorant to claim that every instance of FC is a psuedo form of communication.

What of the individuals who progress from supported communication to independant communications? What of the cases in the past of validation in order for individuals to testify in court cases?

What of on a smaller scale of validation in every day circumstances such as answering questions the facilitator has no way of knowing?

And thirdly: I find the morality of casting a blanket statement over an entire form of communication to be quite alarming, ignorant and above all else, limiting.

By having FC accessible this young man has taken control of his life. He makes decisions for himself, often decisions that we, his facilitators, oppose or are reluctant to pursue on his behalf, but which we do because we believe in providing him as much autonomy in his life as possible.

By having FC accessible he has built friendships, familial bonds, he has a girlfriend and has attended university. These relationships and experiences deserve the respect provided to everyone else which is a freedom to communicate effectively and freely.

With out FC his relationships would be stunted, can you really know someone if you dont know their thoughts and opinions about the world around them? Can they contribute to their communities in a meaningful way? Can they expect to have their wishes and desires to be fulfilled.

No, not really.

I urge your organisation to

a) redefine FC in an objective manner

b) keep an open mind around FC and instead of researching about why it doesnt work put the resources into finding out when it does work and how to improve it!!!

C) do not cast a blanket statement of invalidity over an entire means of communication! Even those opposed to FC must realise that there has to be some exceptions to their limited POV?

I write this email in the hope that this damaging statement may be rescinded and for there to be a shift in the approach to the way of thinking surrounding FC in organizations such as yours.

Sincerely

Lori pumpa

June 20, 2018

Manuel and Ana Santoyo

mom2jab@yahoo.com

To: ASHA Board of Directors

Re: Proposal by ASHA Ad Hoc Committee on FC and RPM

We are writing to you as parent's of a non speaking autistic child. Our daughter is 16 years old. She was diagnosed with epilepsy before she was a year old. Genetic testing also revealed she has a rare chromosome disorder. This past school year after being assessed by an occupational therapist we learned that she has another disorder that has been afflicting her all of her life - dyspraxia.

Both FC and RPM are methods we sought when conventional therapies were ineffective. By age 9, and after over 6 years of therapy, both private and school based, our daughter was still unable to communicate expressively and unable to access Proloquo2go on her iPad effectively. It was FC that we first explored. We learned FC alongside expert trainers and practiced under their guidance. By providing physical support we discovered that our daughter was "in there".

Within the year of this revelation, we turned to RPM in order to learn how to best teach our daughter. Her attention was poor and she moved too fast, always reacting to what was presented to her without discriminating. We first worked with Soma in 2012. RPM teaching methodology supports students with sensory and movement differences. We began teaching our daughter age/grade appropriate content through daily lessons at home and she began to communicate her own thoughts to us with more ease by her 12th birthday.

Since finding her voice our daughter was removed from a restrictive NPS placement and fully included in a small Catholic school for 7th and 8th grade with the support of a communication and regulation partner. For the first time in her life, our daughter had access to the general education curriculum. She not only met grade level expectations, in reading, she exceeded them. In this placement, her behaviors dramatically decreased, and in many ways, she was just like a typical middle school girl! This never would have been possible without FC and RPM.

What we find most disturbing about the proposals is that they assume non-speaking individuals are incompetent. Non speaking does not mean non thinking. We believe all professionals who work with children should practice the least dangerous assumption.

How my daughter chooses to communicate is an inalienable right that cannot be altered or taken away. We consider these proposals a threat and hence a violation of her rights. We urge you to do the right thing and revoke these biased, discriminatory, and unethical proposals. Apologize now for the harm they have caused. Concerning for ASHA; however, is that these proposals were not done in poor judgement, it's authors have a long standing bias against the non speaking community and the supports that they need to communicate. We believe legal recourse to be a logical and needed consequence for these egregious efforts.

Sincerely,

Manuel and Ana Santoyo

June 24, 2018

Carol Thorne

carol.thorne1@bigpond.com

I wish to address the Proposed ASHA Position Statement: Facilitated Communication (FC.

My son was introduced to this form of communication (F.C) some 11 years ago with the Qwerty BOARD and recently to the IPAD. He has always used some form of FC as communication e.g. pointing to picture cards, pictures and words, Items, with assistants to the hand and arm. You see he has limited movements due to his disability, but he has a bright mind. These systems have /had been put into place for use by a speech Therapist.

We have spent quite a lot of time and money of different devices to assist him over the years not to mention the cost of professional support as well as assessments to prove that he has capacity for choice and decision making.

He has gone through all his younger life and schooling without a great deal of support from teachers/ therapists to use all the different forms / systems of communication. Teachers did not have the time or willingness to use the systems and Therapist time was very limited. It was easier for everyone to just talk to him and expect limited response because he has a disability. Which is still happening today for children who are non-verbal? It is and was very frustration and hurtful when after he left school and found the QWERTY board and how to use it with assistants to be told "Yes we always knew he was a very intelligent person." Now the so called Professionals which to take away the only way people can be seen as individual like we all are. Just because people with a disability are non-verbal does not meant they have no brain or intelligence.

We have not always had people who are able to use F.C with him; they have had training and still are unable to use the system. Not everyone is able to use it. Our son will not allow people to work with him if they do not believe that he has the ability to communicate. If he does not trust the person/s he will refuse to move his hand for them.

It disappoints me immensely when I hear all of these comments from Professionals making these bold and broad statements. Who are they to take away the only positive thing to happen for people with a disability to be seen as a person who is able to have a conversation with other people like we all do? It is called being seen as a **valued person** like they are no different, only they are non – verbal.

I wonder how they would fell if they were called to questions about their qualification to make such statements. How all the different interrupters would be seen if they were questions on their replies to what is being spoken, as not everyone can interrupt different languages or sign language? These are never questions. **WHY**

I strongly object to people trying to take away the form of communication from people. Our son is now a person in his own right, making decisions, directing staff, speaking to friends, being an advocate for people with a disability. Having conversations with friends and family, it has taken a long time for him to have the belief in himself to develop these skills with confidence that he will be believe. He has a quality of life like his brothers and sisters.

I urge all the professionals who are working with People with a disability to see them as individuals first and not their Disability. As the disability does not determine who they are, we should not be so early to judge. Everyone around them knows they have a disability, but they also have lots of abilities that just need to be unlocked. I know from experience of the years of working in the area of disability.

It all comes back to the statement is used so readily. "Person Centred Approach", but it is just words, because if it was used correctly we would view people with a disability quite differently. Also" Social Role Valorisation "people being seen as valued members of our society. Both of these make you view things differently.

Pray for Change

Carol Thorne

P.S I also have worked with Speech Therapist, Occupational Therapist who work with this form of communication and have found it to be very enlightening and encouragement to see the development in the individuals who use this system. They grow and strength in them is amazing.

June 21, 2018

carol.thorne1@bigpond.com

American Speech-Language-Hearing Association

Attn : Board of Director

I look at FC as a doorway that has been opened to a whole new world for people without a voice. I see everyday what it does for the young man that I work for. He is a talented author, poet, an has the most wicked sense of humour which he uses FC to express. He does FC with lots of different people, an for me personally he just amazes me what he expresses through his trusted board an also his IPad. He sends texts to friends an family, talks on social media, an is such a part of everyday life. FC is a life line for all people without a voice, to happiness.

June 24, 2018

Laurence Le Blet

joncourleblet@wanadoo.fr

Please don't me call crazy!

Like every Saturday night I hope my son who, is 18, won't ask to go to church. We, his parents, are profoundly atheist (as many people in France) would have to go with him and it is not easy for us. But why doesn't he go there by his own, you could ask? Because he is disabled and since he is a believer and faith is important for him, and since he can't go without support, we go with him, even if we are profoundly atheist .And we know about his faith because he tells us …or should I say, he types us about it; yes, because he can't talk; he is a non-verbal autistic young man who communicates by typing. So when you doubt about kids who type to communicate with a letter board , saying that these kids can't express such things like faith, for example , it is just like you were saying that I 'm crazy ! Why, on earth, am I going to church, being atheist! Do I lie to myself? If all of this was just   like clever Hans effect, I should have chosen another place to go on Sunday morning!

Silent fighters

There are some non-verbal autistics who type to communicate, who share their experience through social network for example.
It is usually their parents who have been able to discover their ignored abilities. Presume skills: that is, do not stop at the behavior. Their journeys are very poignant to follow and an increasingly large community shares these stories. These are very rewarding and motivating experiences.

But these non-verbal autistics are not really taken seriously. The question is why? Do those who doubt come to see and share some moments with these kids: NO; do they understand that life has changed for family since their kids types, spelled? No; they don't know anything about family discussions at lunch, after watching a movie, through a letterboard or ipad. They don't know anything about the way you reach your kid mind, in everyday life, so naturally since you see your kid like he is, really. For those professionals who doubt, it is merely a professional misconduct to presume competence, to talk with an age appropriated tone to a kid they see as a toddler. They really can't propose high level academic material to someone they don't see as intelligent. **But maybe professional misconduct is not to go beyond prejudices.**

Recent research and increasingly frequent testimonies tend to show that these individuals have potential that would allow them to access school, university. Recently, IMFAR 2010/2011 (International Meeting for Autism Research) focused on non-verbal autism and questioning their potential. (http://www.thinkingautismguide.com/2011/05/imfar-2011-characterizing-cognition-in_12.html).

John Connolly's lab (McMaster University, Canada) used the same analytical tools (such as EEG) that he uses to assess the state of consciousness and language abilities of locked-in-syndrome patients. , with nonverbal autistic children. The first results are very encouraging and show some unexpected capabilities of language analysis.

The team of Laurent Mottron evaluated with tests more adapted to the profiles of autistic nonverbal children of specialized classes. A significant number showed abilities that questioned their educational orientation. (Courchesne, 2012).

"Although we are loud and clear that autism and intellectual disability are distinct, autism interventions are still in the shadow of intellectual disability. (Brigitte Harrisson, p.36)
What these silent fighters say (Tito, Ido, Drew, Jeremy, Carly, Naoki,…) is that they are there. Their autistic manifestations are not apprehended as autistic identity, as adaptations but as signs of debility. We do not consider them as individuals capable of understanding: "low-functioning / low expectations".

Non-verbal autistic people also begin to judge their "therapies". The remarkable testimony of Ido Kedar (2012) is awesome and makes us understand a great deal about the behavior and reactions of these individuals. Ido evokes his motor problems, his inability to control his actions, which, in the eyes of his therapists, make him look like a " person with intellectual disabilities ». His frustration at being unable to really communicate his thoughts (to show that he understands everything that is said about him) caused behavioral disturbances that only reinforced the opinion of the therapists on his apparent disability.

Some researches show that, in some case, approaches that have allowed many non-verbal autists to prove their intellectual abilities are diverting the obstacles that arise from their motor and sensory disorders.

(https://www.frontiersin.org/research-topics/801/autism-the-movement-perspective)

It is a true Copernican revolution, a radical change of point of view: to try to realize that what appears to be of a behavioral nature (gestures, attitudes, etc ...) returns to motor and sensory disorders. And so change your attitude towards these silent fighters. I'm deeply moved by their fight because I'm a French mother of a nonverbal autistic young man …who types to communicate. I've taught him everything he knows (literacy, mathematics, etc...), fighting for the few hours he could pretend at school. We had to fight against haters, who thought I was crazy and my son dumb. But last year my son has been the first non-verbal autistic teen to have his " Baccalauréat" , the diploma needed to go to university in France , and moreover the specialty scientific one , the most difficult and recognized diploma ; Today he is a student , changing mind about "low functioning " autism . And he loves going to University, like he loves going to church, yes, he types us he wants to be part of the world: would you hear him?

Sincerely,

Laurence Le Blet

June 24, 2018

Ian Summerville

ian.thea@bigpond.com

To the Board of Governance and the Ethics committee, ASHA.

I wish to comment on the review on Facilitated Communication (FC) being carried out by an ASHA Ad Hoc Committee, and plead with the Board of Governance and members of the Ethics Committee to consider the negative impact that the committee's position statement will have on the lives of many FC users if the recommendations are accepted.

I have read the relevant information provided on the website, including the committee's position statement with its list of "negative and harmful consequences".

As the mother of a 40 year old user of Facilitated Communication Training (FCT), I find it shocking and incomprehensible that an organisation that purports to uphold the principles of human rights would consider putting a blanket prohibition on the use of FCT by speech pathologists and other allied health professionals. Whilst I am writing from Australia, it is inevitable that such a significant decision made by a prestigious organisation in the USA would have repercussions here.

I am not an academic nor an allied health professional, but as the pro-active mother and strong advocate of a gentleman with choreo-athetoid cerebral palsy (severe movement disorder, tactile defensiveness) with high physical support and complex health and communication needs, I have worked tirelessly to maximise opportunities to help him overcome the enormous challenges that his multiple disabilities present. As a child he was assessed as being "intellectually unassessible" because the severity of his uncontrolled movement made it impossible for him to give any consistent controlled response. From age 2, my son has worked with numerous speech pathologists (non-FCT practitioners and FCT practitioners), occupational therapists and other allied health professionals. Our family has financed, and continues to finance physical therapies that might help him assume independent control of his movements. Along with the 12 year lead-up into his break-through into FCT at age 28, we have continued to investigate independent AAC methods through device trials and equipment purchases, along with intensive exercise and movement programs, at significant financial cost. We continue our search for a technology that will give my son independent access to a voice.

The end result has been that after 30 years of investigating a wide range of switches, he can use head / shoulder switches, to indicate only "Yes/ No" or make simple choices. After four years working with a number of Tobii eye gaze programs, he still struggles to even get a satisfactory calibration, and the time-lapse required to actually spell out a single word makes these programs and devices totally ineffective as realistic communication tools. Still, he perseveres with practice, hoping to improve his eye focus.

By contrast, through the use of FCT, he has gradually progressed from "Yes/No" and simple choices, to more choices, and eventually to a large, specially created alphabet board. His principal facilitators over the last 12 years (two qualified instructors, an advanced trained facilitator, and a very proficient basic trained facilitator) have adhered to a strict code of ethics, with communication sessions documented, and with independent validations carried out by three speech pathologists / FCT practitioners with very little or no knowledge of my son, and drawn from different regions of the state.

How can an FCT sceptic challenge the authenticity of the following statement, made by my son during a meeting with a government disability services officer discussing the possibility of removing my son's individual funding and replacing it with block funding? "Please don't take away my funding. It is part of my identity." (My son still retains his individual funding!)

And during a session with a solicitor for my son to give Enduring Power of Attorney to my husband and me, the solicitor was reading the conditions of the EPOA and said "And if it be judged that ----". My son, who was listening intently while grasping his facilitator's hand interjected with "But who is the judge?"

Or during an appointment with a dietician, who suggested that because my son burnt up so much energy through his constant movement and high tone, any sweet treats between meals should be replaced with carbohydrates. Again, he interrupted to say, "Please don't take away my sweets. I really do enjoy them."

I could quote many such instances (and the majority of them are documented) including some where the facilitator was obviously embarrassed by what my son had said. E.g. When a particular support worker was leaving, my son commented "He's a silly bugger, but I wish him well."

Or when his niece asked him what his favourite animal was. His answer "A bronco" (a term not commonly used in Australia except for a football team.) When he was asked "Why a bronco? Why not just a horse?" he answered "Because a bronco is wild and free."

With respect, I would challenge the following statements made in the position statement:

- " --- extensive evidence of harms related to the use of FCT" & "lead to false allegations of sexual abuse and other harms"

I would contend that the evidence of harm relating to the use of FCT is no greater comparatively, and probably less so, than the evidence of harm existing in all other areas of society, particularly when considering sexual abuse. (Consider the many reporters of abuse in religious organisations who were ignored. And yes, perhaps there were some accusers who were dishonest. But have religious organisations been closed down, despite the horrific sexual abuse that has occurred within?) It was an FCT user (Peter Rowe) who first raised the alarm on the endemic physical, emotional and sexual abuse in a Queensland (Australia) institution, leading to the criminal conviction of a number of abusers, and the closure of the institution.

Ideally, my son would love to be able to use a motorised wheel chair, but until he can develop consistent switch control, this is out of his reach. He is constantly at risk of abuse by the fact that he is pushed about in a wheel chair and cannot verbally object if he is taken places that are not of his choice. So do we leave him confined to his bed because he is at risk of being abused by being taken places he does not want to be, or that may put him in physical or moral danger?

Similarly, do we leave him, vulnerable in his total dependency for all his needs, to be a victim of sexual and other forms of abuse, with no means of reporting this, by refusing to give him a voice through FCT, because he requires hand support from a facilitator, and there is a slight chance that he just might, one day, misreport? This, I might say, is a guaranteed way for the abusers to win without any fear of retribution!

- “there has been no evidence of benefit”

On the contrary, since my son has been given a real voice through FCT, he participates in reviewing new staff so that anyone he does not feel comfortable with is rejected at an early stage of employment. Consequently, he has never had to report mistreatment or abuse. But he does use his communication sessions to give feedback, and offers constructive criticism where/when required e.g. “Please ask the staff not to leave me hanging in the hoist while they change my bed.”

He has also been given a purpose in life because he writes short stories, presents at schools (answering questions that no one without his degree of disability could possibly answer), keeps in touch with distant family through social media (building a network of future advocates for when I am no longer around, and establishing long-term safeguards), can communicate his health needs clearly so that a diagnosis and appropriate treatment is prompt and accurate, has developed a keen interest in astronomy and has expressed a wish to expand his knowledge of literature.

- “may also hinder or delay access to appropriate services and effective forms of intervention, including augmentative”

At no time have other forms of AAC been ignored, nor has FCT delayed access to appropriate services. When one lives in a regional centre in Queensland, one is limited to the services available. All opportunities to access professional services have been pursued, with several speech pathologists and occupational therapists feeling frustrated that their efforts have not culminated in greater success. (One OT, after a single visit, said that there was nothing more that she could offer.) In fact, every one of them has been appreciative of the fact that they can actually communicate with my son through his FCT with a trained communication partner, to assist them in understanding his challenges. Every one of these professionals has stated that they have no doubt that the feedback is genuinely from my son.

- “denies the users’ access to their human right of communication”

It seems, according to the committee’s position statement, that my son’s struggle to independently give a simple “yes/no” on switches provides satisfactory access to his human right to communication, yet allowing him to express himself in a full and comprehensive way through FCT somehow denies him that right! I find this position totally incomprehensible. The committee would doom him to the life of silence (other than a yes/no or choosing a simple option) that he experienced for 28 years as he monotonously practices his switches and eye-gaze, day in, day out. It seems that it is preferred, from a human rights perspective, that he should be content with choosing “orange juice/apple juice” rather than to say “I’d prefer a cup of tea.” The latter, according to the committee, denies him his human right because FCT is unreliable and exposes him to abuse!!!! How can one possibly make sense of this argument?

I quote from one of my son's earliest writings in 2012, about the time he announced that he wanted to be a published author:

To Somebody Not Looking

He is dumb.
There’s nothing upstairs.
I wonder if he can hear me?
It’s ok to talk about him, he doesn’t understand a word.
Let’s talk to him in baby talk, it might calm him down.
He’s had a poo and spread it everywhere. God it stinks!
All he does is fight with me.
He is useless.

To Somebody Who Sees

I am intelligent.
I am valued.
I can hear you, and I understand.
I like to be addressed the same way as any other adult.
My bowel motions smell bad, just like anyone else’s.
My movement is not always under my control.
I am useful.
I have a brain, and I have a heart.
I am a human.

- “supplant other forms of effective communication”

How does FCT supplant other forms of effective communication when, to date, conscientious efforts to actually **find** another method of “effective communication” have failed?

I feel distraught that an organisation that seemingly exists to promote communication for all, should discount a communication method that, for some people, is the **only** effective method of communication. I would suggest that, rather than let fears and apprehension dictate the organisation’s position, a better option would be to advocate that all FCT users have as many proficient facilitators as possible so that validation is occurring constantly, thereby eliminating any of the potential harms that so concern the committee.

The answer is not to deprive people with complex communication needs of a voice, whatever form that might take, but to ensure that practitioners are well trained and qualified, that they are bound by a strict code of ethics, that they are part of a team of facilitators and do nor operate in isolation, and that families and advocates are well informed and are an integral part of the communication team.

e.g. Recently I questioned the fact that a support worker had taken my son to a “lawnmower races” event, saying that it was Tony’s choice (yes/no). Since my son has hypersensitive hearing and is generally averse to loud nosies and it was also hot weather, to which my son is particularly sensitive, I was sceptical. I wondered if he had been manipulated. At his next FCT session with the qualified instructor, I expressed my surprise that he would have chosen to go to such an event, and asked what it was like.

He said “It was terrible! “ (laughter all round) “It was noisy, hot and dusty”. I said that I’d have expected him to anticipate this, and I didn’t understand his choosing to go. His response was “It was a bloke thing!” (He lives with two other men, and the two support workers and one volunteer that day were also men.)

I would hope that the ASHA Board of Governance and members look further than what appears to be a very narrow, and seemingly prejudiced view by a committee that has been selective in its choice of “evidence” to support its argument, and appear blind to the fact that not every person with CCNs is fortunate enough to be able to access any of the array of communication devices currently on the market. For some, the dream of a technology that will give them an independent voice, is still an allusive one.

Thank you for this opportunity to give input to this critical discussion. I sincerely hope that my son’s story will help influence ASHA to discount the proposal of the Ad Hoc committee. I fear that acceptance of their position statement would have a disastrous effect on some of the most vulnerable in our society.

Kind regards,

Thea Summerville

June 24, 2018

Joy Scheu

tobeginagain4@yahoo.com

Dear ASHA,

I am a single mother of three children who all need help with communication. I have a non-speaking son with Autism a son with Autism who is unreliably speaking and a third son with a genetic disorder that makes communication difficult. I also teach at a school for children with a variety of special needs that make communication difficult including non-speaking and unreliably speaking students. As you can read I am a very busy woman and yet on top of the regular daily tasks of caring for my children and my students I have made **connection** my mission. You see connection is the gold of communication. It is more than a colored icon on an I-pad that my sons used. It is more than making first-letter sounds to express their very basic needs. Connection is the gold that I longed for while I sat for countless hours in a waiting room of a speech therapist office. Connection is the gold that I longed for as I opened my home to countless hours of ABA therapist. Neither of these methods ever brought even a fraction of the connection that my family now relishes due to spelling to communicate.

In response to your position statement to not consider the information obtained during RPM as the voice of the person with a disability I say shame on you for your attempts to discredit these amazing humans very words! Their words! Words that I watch my boys and my students, every day, choose to work hard to spell out. The idea that these could be my words is, put simply, false. Again, for me it about connection. How could a conversation lead to connection if the spelled words are my thoughts? This would stand right up against my own personal mission and I would have to throw the method out and yet I have not and will not because this is simply not what is happening. ASHA you are missing the point because you are coating communication in clinical sterility and not remembering the beauty of your own mission statement to advocate for your members and those they serve. According to lines 78 and 79 of your proposal you reviewed “literature” relating to RPM. I do not see where you connected with the people. I would implore you to do so. In response to lines 87 through 92, I would like to invite you again to connect with the people. I have watched time and again as my sons have used the boards to communicate during times of anxiety or pain exactly where they need help and watched as peace comes to their bodies as I am able to attend to their need specifically. This was never achieved before with any of the other methods of communication in our home. I have also watched the joy that comes over their faces as they are now able to participate in family game time by using the boards to answer trivia questions.

Throughout the proposal it is stated that there is lack of scientific evidence to validate RPM. I am not a scientist, lawyer or therapist but it sounds like you are asking your ASHA members to warn their clients against something that you have deemed harmful without having any scientific evidence that it is. Whatever the outcome our family will continue to use spelling to communicate. Nothing ASHA decides can take away the gold that our family has dug up over this last life-altering year. I would ask that instead of instilling fear you instill hope and support and protect my family and other families that now know the beauty of connection through spelling to communicate.

Thank You,

Joy Scheu

June 24, 2018

Robert van der Ham

vanderham55@hotmail.com

Do you agree with the proposed position that FC should not be used?
Yes No

Position Comments

We are the parents of a 30y/o man with ASD and severe communication deficits. We have tried numerous communication strategies over the years and FC has been the most sucessful. It is difficult to access and has significant limitation due to the substantial training requiremants for people who are his support workers. There are instances where individuals are still supported but there support is part of the routine. They are very actively involved in the communication event, focused at typing and very engaged in the conversation. And there are others where the event is more fragile and more distracted by their autism. But in the case of our son his progress has allowed thim to be more consistent in his communication. His autism will always play a part in his interaction with people he comes in contact with but he will have a voice.

Do you have any comments about the FC definition? If so, please provide below.

The FC definition needs further explanation outlining the problems of autism related to possible movement disorders , auditory distortions, various sensory issues, planning issues and a host of other issues that present with different individuals. Having an insight into those parameters will allow an individual to better understand the underlying theory rather simple definition of "physical support"
Do you consider the information presented in the “Systematic Review of FC” section of the statement to be current and suitable for the purposes of the position statement?
Yes No

Systematic Review Comments

I believe that FC needs a significantly different approach to test the validity of FC. In the past the accepted scientific studies are seriously flawed. I believe there should be more collection and analysis on anecdotal evidence which gives a more representative evaluation of FC.

Do you agree with the recommendations?
Yes No

Recommendation Comments

I believe SLP's require significant understanding and training in the underlying principles that underpin the foundation of FC. If this training was offered and the obvious bias was put aside then FC could be a valid option for people.

What impact, if any, do you think the proposed position statement on FC will have on your work or the work of others in supporting communication?

It continues to promote ignorance and misinformation and continued bias for FC. It will continue to disadvantage persons who use FC and reduces the opportunities for access to effective and appropriate treatment

Cheers

June 15, 2018

Lisa Romaine

lromaine@celebratethechildren.org

To Whom it May Concern,

We are a school for children with alternative learning styles in North Jersey. Our school services approximately 130 students, many of whom have complex communication needs. Of these 130 students, 45 participate in using Facilitated Communication or the Rapid Prompt Method.

The foundation of our program is the Developmental Individual difference Relationship (D.I.R.) model. We offer many interventions and modes of communication to our students, including, but not limited to, picture based low tech and high tech systems, sign language, eye gaze/tracking, PROMPT, letter boards utilizing the Rapid Prompt Method (RPM) and Facilitated Communication (FC). All of these options are available for all of our students to trial and/or utilize if deemed appropriate and with appropriate parental consent.

We have found that using RPM and FC has greatly improved the communication ability of many of our most complex students. When other methods fail, these methods have been successful. Motor planning and movement disorders are an underlying cause of communication systems failing our students. Initiation, impulsiveness, eye/hand coordination, among other movement issues all impact a person’s ability to access communication effectively. When giving appropriate support, students are able to access their devices and/or letter boards with much more accuracy and success. Being successful has reduced behaviors tremendously, often immediately. This has enabled our students to participate in classes and activities previously inaccessible to them.

With the ultimate goal of independence, our students have measurable goals that are evaluated three times per school year. Staff and families are trained in how to appropriately support a students communication throughout the day according to best practices outlined by the Institute of Communication and Inclusion (for FC) in Syracuse, NY and Halo in Austin, Texas (for RPM). Safety measures are put in place through school policy to safeguard and confirm unclear, ambiguous or concerning communication which may be typed by a student. We have had instances of confirmed and unconfirmed typing by students using these precautionary measures.

Overall, the quality of life of each individual student and their families has been impacted positively by the introduction of supported typing whether it be in the form of RPM or FC. Their self esteem has improved, their willingness to participate in appropriate activities has increased. Their self advocacy has helped staff tailor their program based on their input with much success, success that would be unachievable without their input.

Every student that we work with has had several instances of communicating information unknown to the facilitator which was later confirmed by family or other staff members. All of our students also participate in message passing activities when they are ready. We have several students who are able to message pass in a structured setting with accuracy between 75 and 100 percent. This clearly shows their communication is coming from them and not their support person.

Taking effective communication away from these students would have a hugely negative impact on their lives. It would be a travesty for them and their families. They would no longer be able to participate in age appropriate activities/academics, they would not be able to have a voice in their programming or their futures. They would be unable to build friendships and social relationships with others. They would have to depend on others to make decisions (often inappropriate) on their behalf. It would force them into programs that warehouse individuals with disabilities instead of capitalizing on their talents and ambitions to be productive members of society. It would cause them to act out in frustration, due to lack of communication and be perceived as incompetent. Their behavior would indicate medication in some cases, medication that can cause further problems when effective communication was working previously.

We are extremely disappointed and concerned that the Ad Hoc committee has refused to consider input from users of these methodologies. In our opinion, policy decisions of such magnitude should involve a careful and unbiased examination of viewpoints. We have several adult students that would be happy to participate in a panel discussion or send video to share their experiences with these methodologies and show how their lives have been positively impacted and would be negatively impacted should their communication be taken away.

Based on the above, we encourage ASHA to withdraw their proposed statements. The Civil Rights of individuals with disabilities have already been compromised by these statements with further damage at stake should these statements remain as they are.

We end this letter with great concern for all those who will be impacted. Please consider them when making your decisions.

Thank you.

June 24, 2018

Lisa Guardado

lisaguardado18@gmail.com

Dear ASHA,

I would like to take the opportunity to express my concerns about the upcoming proposal and campaign against RPM and alternative forms of communication. I have personally benefited from spelling on letter boards. Though I have only been using letter boards for about 2 years, it has changed my life dramatically.

I am a thirteen year old who was diagnosed with autism at the age of two. My families world was turned upside down when I started with ABA, I was receiving 40 hours of 1:1 ABA therapy per week. My parents also had me participate in various other therapies. Such as occupational, speech, vision, and biomedical treatments. They did everything possible to help me. This went on for years. But I was still unable to use my voice. Can you imagine knowing lots of information and all of your thoughts but be unable to share it with anyone?

A good friend of my parents shared with them about RPM. We flew to Georgia to see what it was all about. At first I was worried that it would like other therapies and my voice would stay locked. You can’t believe the feeling of talking to your family really for the first time. It has been an exciting time for me to share everything with my family, friends, and teachers.

I cannot emphasize enough how letter boards has played a vital role in opening up this opportunity for others to hear my own thoughts and voice. Please do not take this new found freedom away from me.

Thank you for your time.

Sincerely,

A Letter Boarder

June 24, 2018

edge2127@aol.com

Dear ASHA,

As I sat and watched my daughter swim in the pool yesterday, I was reflecting on the past year and a half of her life. She was diagnosed with autism at age of two and never really had any speech. So many times she wanted to tell us what she was feeling, but not able to get her words out. We could always see a light in her.

It wasn’t until December 2016 that we fully realized just how much she was taking in. She started to communicate with us on letterboards and the results were astonishing. We got to meet our 11 year-old daughter for the very first time. She is witty, funny, feisty, an advocate, a feminist and so much more.

To say that her communication is not acceptable is unreal. But that is exactly what is going on. Although the vision of ASHA (American Speech-Language-Hearing Association) is to make effective communication, a human right, accessible and achievable to all—a committee within ASHA is trying to deny my daughter her communication choice.

This committee is made up entirely of individuals who allege that spelled and typed communication by non-speaking individuals is not valid. How is it possible to deny individuals this right.

“Not being able to share these thoughts was disappointing. Then I learned how to spell on the letter boards. This changed everything. Now people can hear the real me.” -My 11 year old daughter

Don’t let this communication be taken away from so many non speaking individuals.

Sincerely,

A Concerned Parent

June 24, 2018

Casey Woodfield

casey.woodfield@gmail.com

American Speech-Language-Hearing Association
Attn: Board of Directors
2200 Research Boulevard
Rockville, MD 20850-3289 USA

Dear ASHA Board of Directors,

I am researcher whose work centers on documenting the experiences of nonspeaking autistic individuals who type or point to communicate. I am also a colleague, educator, research team member, and friend who lives, teaches and works alongside those who use a range of communication methods. I write to you today with deep concern about the proposed position statements on FC and RPM, as well as the process and composition of the Ad Hoc Committee by which these statements were developed.

In time spent with nonspeaking individuals who have learned to type or use letterboards through training in RPM or FC, I have come to not only understand their communication methods, but also the personal histories that preceded use of them. For many, access to these tools has been provided only after years of ineffective trials using other “evidence based” practices. All the while, they missed years of equitable educational and social opportunities; this story continues to repeat itself in schools and communities. Their experiences suggest that, as a field, we can do better in providing a range of communication options-including FC and RPM-from as early on as possible. On the contrary, these position statements threaten to make the process of exploration, practice, skill development and noncontingent access to communication and inclusion increasingly out of reach. If adopted, these policies further limit access to tools that have proven effective for individuals where others have not and violate the fundamental right of communicative choice for nonspeaking people. These potential outcomes stand in stark contrast to ASHA's stated commitment to "making effective communication, a human right, accessible and achievable for all."

As an educational researcher, I am aware of and uphold the importance of establishing an evidence base through quality, peer-reviewed studies. As a person whose research centers experiences of and with nonspeaking autistic individuals who type/point to communicate, I am also aware that evidence of effectiveness of these tools often manifests in varied and nuanced ways, over a timeline that many studies, funding opportunities and publication outlets fail to support. As an example, I spent 3 years studying an inclusive public high school with five students who type to communicate (all of whom demonstrated the ability to type independently, one of whom went from unreliably speaking, to typing, to reliably speaking and using typing as a supplement over the course of his high school career). At no point was the sole purpose of that study to validate the communication of these particular students, but additional outcomes of spending that time closely engaging with their experiences included: evidence of message passing, independent communication, decreased instances of "challenging behavior," proficiency across multiple support partners, and academic achievement that met the same standards as their neurotypical peers. This kind of work takes patience, flexibility, willingness to consider a range of evidence forms and research methods, as well as listening to the people, families and practitioners involved. Not only will the proposed position statements halt further and varied research in this area, but they threaten to impede the communicative access for those voices most important in moving it forward.

What is also not addressed in the position statement is the research base that has contributed to an ever-evolving understanding of FC and RPM, as well as the sensorimotor experiences of those who need and use these tools. Many of the "anecdotal reports" the Ad Hoc Committee references as insufficient evidence, are in fact peer-reviewed studies that rely on a wide range of research methodologies and contribute to a growing conception of what constitutes evidence in this area of the field. Methods such as eye tracking (Grayson, Emerson & Howard- Jones, 2012) and lexical analysis of typed text (Niemi & Kärnä-Lin, 2002;Tuzzi, 2009), have been used to "validate" typed communication. The evolving understanding of sensory and motor challenges in autism has implications for better understanding the need for human-provided prompts for typing/pointing, how to most effectively fade that support over time, and what other strategies (i.e. to support sensory and movement) can augment communication (Donnellan, Hill, & Leary, 2013; Hussman et al., 2011; Leary & Donnellan, 2012; Torres et al., 2013). It has also been documented that some individuals have achieved increased levels of independence and can exert agency over their lives (Ashby et al., 2015; Rossetti et al., 2008; Rubin et al., 2011) and have developed the ability to read their typed text and/or engage in short spoken conversations (Broderick & Kasa-Hendrickson, 2001, Kasa-Hendrickson, Broderick, & Hansen, 2009). Consideration of this literature remains noticeably absent in the proposed position statements. RPM is grounded in and has promise for exemplary educational practice, broadly. FC has contributed to and stands to benefit from the neuroscience research that is currently underway related to movement, motor planning and communication. Along with continuing to support these areas of research, the questions we should be asking are not whether FC and RPM work, but how and under what circumstances, with what supports and for whom. The answers should not involve excluding an entire literature base or group of people. As Cardinal and Falvey (2014) argued, progress hinges on attention to the areas that have emerged as promising and the ability work with one another as a field alongside those who truly are the experts on these practices.

Not only is the Ad Hoc Committee's failure to engage in an unbiased analysis of multiple viewpoints concerning, but so too is composition of the committee itself. The committee members are individuals with histories of making disparaging remarks about FC and RPM, as well as about individuals with disabilities who use these methodologies. Further, the committee itself and the position statements do not include the presence, perspective or any effort to solicit involvement from nonspeaking individuals who type or point to communicate. Over and over again those who use these methods have come forward asking to be asked; using their voices to help create a climate that not only better supports their experiences, but that is grounded in shared understanding and respect. The actions of the Ad Hoc Committee reflect a failure to listen. As an organization supporting the human rights of disabled people, ASHA should be disappointed and concerned with the clear disregard of the historic call by disability rights advocates: "nothing about us, without us." To refuse to consider input or evidence from individuals who use, and ASHA members with experience in, these methodologies directly contradicts ASHA's mission and the human rights of nonspeaking people.

In light of the biased, narrow, and exclusionary process by which these position statements have been developed, I urge ASHA to withdraw the proposed statements immediately. A formal apology should also be issued for the damage that has already been done to the civil rights of individuals with disabilities by the Ad Hoc Committee. There is much work to do, and inherent possibility, in supporting communication as a human right-including the fundamental right to communicative choice-for all people. I, along with my colleagues, friends and students concerned with communication access as a social justice issue, look forward to ASHA's leadership, collaboration and insistence on equity along the way.

Sincerely,

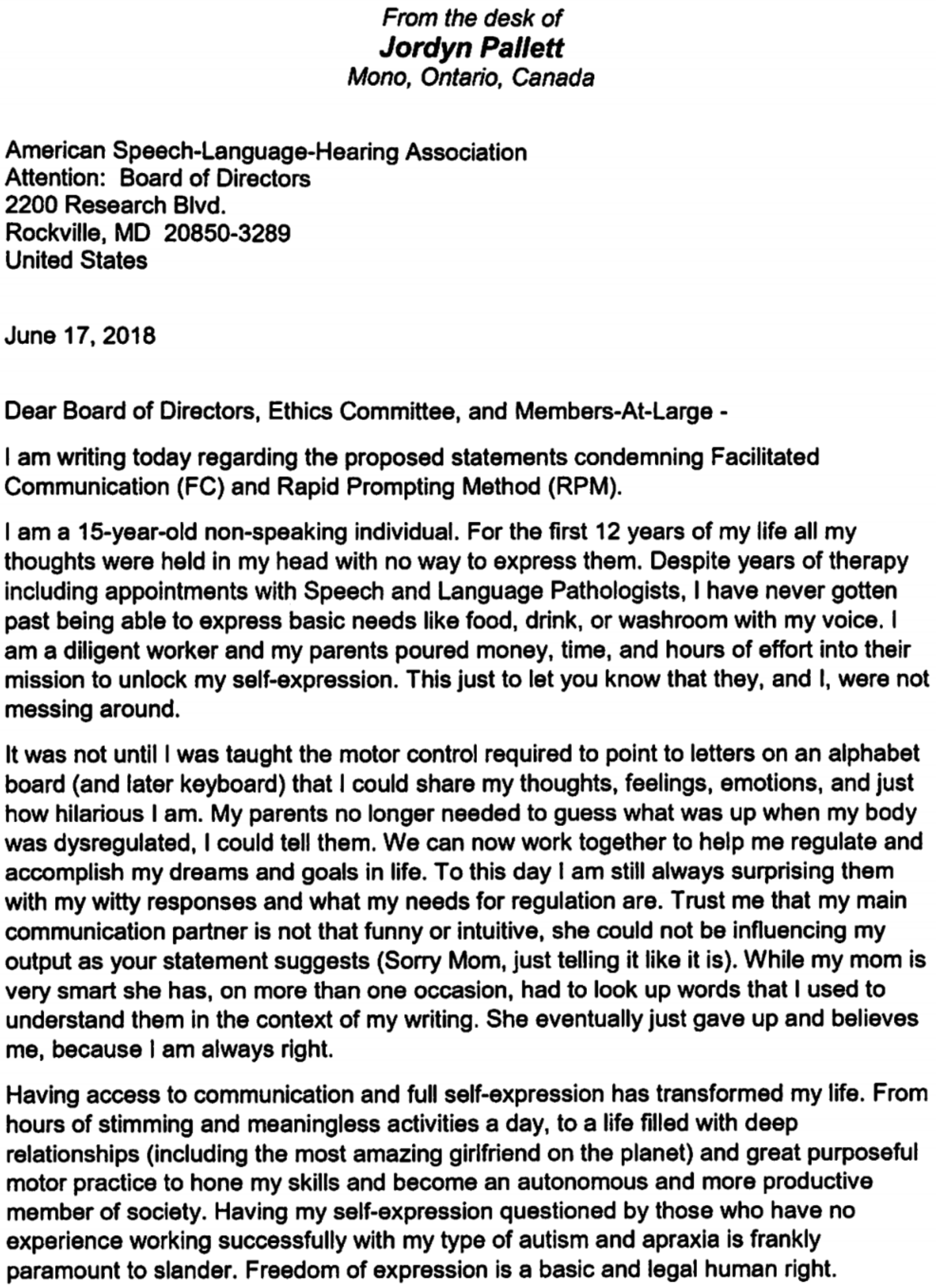
Casey L. Woodfield, Ph.D.

June 17, 2018

Jordyn Pallett

Kelli Pallett

Dr. Tejus Raval



From the desk of
Jordyn Pallett
Mono, Ontario, Canada

American Speech-Language-Hearing Association
Attention: Board of Directors
2200 Research Blvd.
Rockville, MD 20850-3289
United States

June 17, 2018

Dear Board of Directors, Ethics Committee, and Members-At-Large -

I am writing today regarding the proposed statements condemning Facilitated Communication (FC) and Rapid Prompting Method (RPM).

I am a 15-year-old non-speaking individual. For the first 12 years of my life all my thoughts were held in my head with no way to express them. Despite years of therapy including appointments with Speech and Language Pathologists, I have never gotten past being able to express basic needs like food, drink, or washroom with my voice. I am a diligent worker and my parents poured money, time, and hours of effort into their mission to unlock my self-expression. This just to let you know that they, and I, were not messing around.

It was not until I was taught the motor control required to point to letters on an alphabet board (and later keyboard) that I could share my thoughts, feelings, emotions, and just how hilarious I am. My parents no longer needed to guess what was up when my body was dysregulated, I could tell them. We can now work together to help me regulate and accomplish my dreams and goals in life. To this day I am still always surprising them with my witty responses and what my needs for regulation are. Trust me that my main communication partner is not that funny or intuitive, she could not be influencing my output as your statement suggests (Sorry Mom, just telling it like it is). While my mom is very smart she has, on more than one occasion, had to look up words that I used to understand them in the context of my writing. She eventually just gave up and believes me, because I am always right.

Having access to communication and full self-expression has transformed my life. From hours of stimming and meaningless activities a day, to a life filled with deep relationships (including the most amazing girlfriend on the planet) and great purposeful motor practice to hone my skills and become an autonomous and more productive member of society. Having my self-expression questioned by those who have no experience working successfully with my type of autism and apraxia is frankly paramount to slander. Freedom of expression is a basic and legal human right.

Should this position statement pass (which it has in my country) it will not immediately affect me. You see, I am currently home-schooled and have no oversight to prove myself to. However, my peers do not always have the luxury of this option and will be denied access to a way they can demonstrate their acquisition of knowledge and will be relegated to being essentially babysat versus educated. **This is counter to your vision statement - "Making effective communication, a human right, accessible and achievable for all."**

I can only hope that ASHA at-large will not let the biased and inexperienced create an epidemic of trapped voices. The ad hoc committee proposing these statements has refused to consider evidence from users or other members of ASHA with experience with these methods of communication. The members of the committee have also been known to publicly make slanderous disparaging remarks about these methods of communication and even some individuals who use them. I would not call this unbiased.

I encourage you to retract these statements and issue a formal apology to the communities using these forms of communication. The damage of these statements has already affected my peers. You are seen as an authority and should thus be using extreme care and ensuring fair evaluation of methodologies before releasing publicly.

One more thing, I appreciate that you are trying to look out for our best interests. However, doing that without our input makes zero sense. We are sentient beings capable of self-determination and great contributions to society. You would be serving our population and society as a whole to empower our voices to be heard and strongly believed.

Yours passionately,

Jordyn Pallett

Cc: ASHA Ethics, ASHA Governance

June 24, 2018

American Speech-Language-Hearing Association
Attn: Board of Directors
2200 Research Boulevard
Rockville, MD 20850-3289

RE: Response to Draft Position Statements on RPM and FC

Dear Board of Directors and ASHA Members at Large –

I am writing you to request that you withdraw the draft position statement not recommending the use of Rapid Prompting Method (RPM) and Facilitated Communication (FC). Furthermore, I urge you to consider that communication through pointing to letters on an alphabet board (or typed) is in fact the voice of a person with a disability and should thus be honoured. As the mother or a 15-year-old essentially non-speaking boy, I find these statements very concerning and believe that more research should be done, and first-hand testimony should be viewed, before a position is taken.

My son was diagnosed with autism before the age of 2. Since that day we have explored a number of therapeutic modalities to support him in having a full and productive life, focussing primarily on giving him a reliable way to access his self-expression. This has included working with a Speech & Language Pathologist, who assisted us with his phonology, but could not unlock his ability to initiate self-expression. He could, after years of work, express his basic wants – food, drink, washroom in one-word utterances and sometimes when pressed a rote sentence. While this is useful it is so limiting and left us with always guessing what was happening with him physically when he appeared unwell.

Through teaching his gross motor to point to letters on a letter board, he has accessed that self-expression we always knew was in there. Trapped until the age of 12.5, his voice was finally unleashed, our guessing game was over, and a whole new world opened to him and us as a family.

Where before his days were spent mostly stimming with glimmers of connection, that are now filled and fulfilling with access to his self-expression. He composes blogs, poetry, and manages and online social media presence. He learns with peers online about subjects he adores – literature, religion, math, and history and now speaks of graduating high-school and accessing post graduate education. We play board games and he partakes in the witty table talk that accompanies these games with family and friends. He directs his therapists (Osteopath, Chiropractor, Movement Specialist, Personal Trainer, etc.) such that he receives the input and assistance that he needs to best harness and build the purposeful motor pathways required for him to have better control of his body. He participates in all his medical appointments.

His control over his body has grown with access to expressing himself. In situations where would have before understood the impulsive actions of his body to mean that he wanted "out" or "away", he is now able to express that he is excited and what assistance he needs such that he can participate in these activities – rock climbing, attending a NBA basketball game, paddling in a kayak, going down a water slide – are just a few examples. All this to say, that his life and ours has completely transformed from one of existing and surviving to one of creating and thriving.

In all our interactions over the last 2.5 years not one person (autism professional or otherwise), has ever questioned that his communication is his own. He interacts with his own brand of direct humour and compassionate understanding that only leaves people awed, moved, or looking up vocabulary they didn't know. As his primary communication partner, I can not make this stuff up, and his expression stays consistent with other trained partners.

By stating that the use of these communication modalities is not recommended, a percentage of your clientele's options are being limited to modalities which may not ever work for their needs. Furthermore, this may influence the educational sector to withdraw the supports required by this population where they are currently in place. This is counter to ASHA's vision statement, "Making effective communication, a human right, accessible and achievable for all". Additionally, it counters ASHA's Principle of Ethics I, "Individuals shall honor their responsibility to hold paramount the welfare of persons they serve professionally". By deeming these techniques inconsistent with "the communication rights of autonomy and freedom of expression" and saying that communication through these modalities "should not be considered as the voice of the person with a disability", the ad hoc committee has in effect disavowed any testimony from the individuals they purport to be protecting.

To systematically review of only some of the available literature about these communication methods, which the committee reports to "[fail] inclusion criteria due to poor research design, [and lack of] sufficient controls to determine treatment effects", and then make conclusive policy changing statements does not follow ASHA's definition of evidence-based practice "the integration of research evidence with practitioner expertise and client preferences and values into the process of making clinical decisions". An absence of research evidence does not equal evidence of the absence of efficacy. A proper review would include witnessing the use of the modalities first hand, interviewing those that practice the modalities professionally and those that communicate using them. Policy decisions of this magnitude should involve a careful and unbiased examination of **all** viewpoints. Instead, it appears that this ad hoc committee, comprised of individuals who have histories of personally making disparaging remarks about these two methodologies, and even some individuals who use them, have picked the "evidence" to back up their opinion.

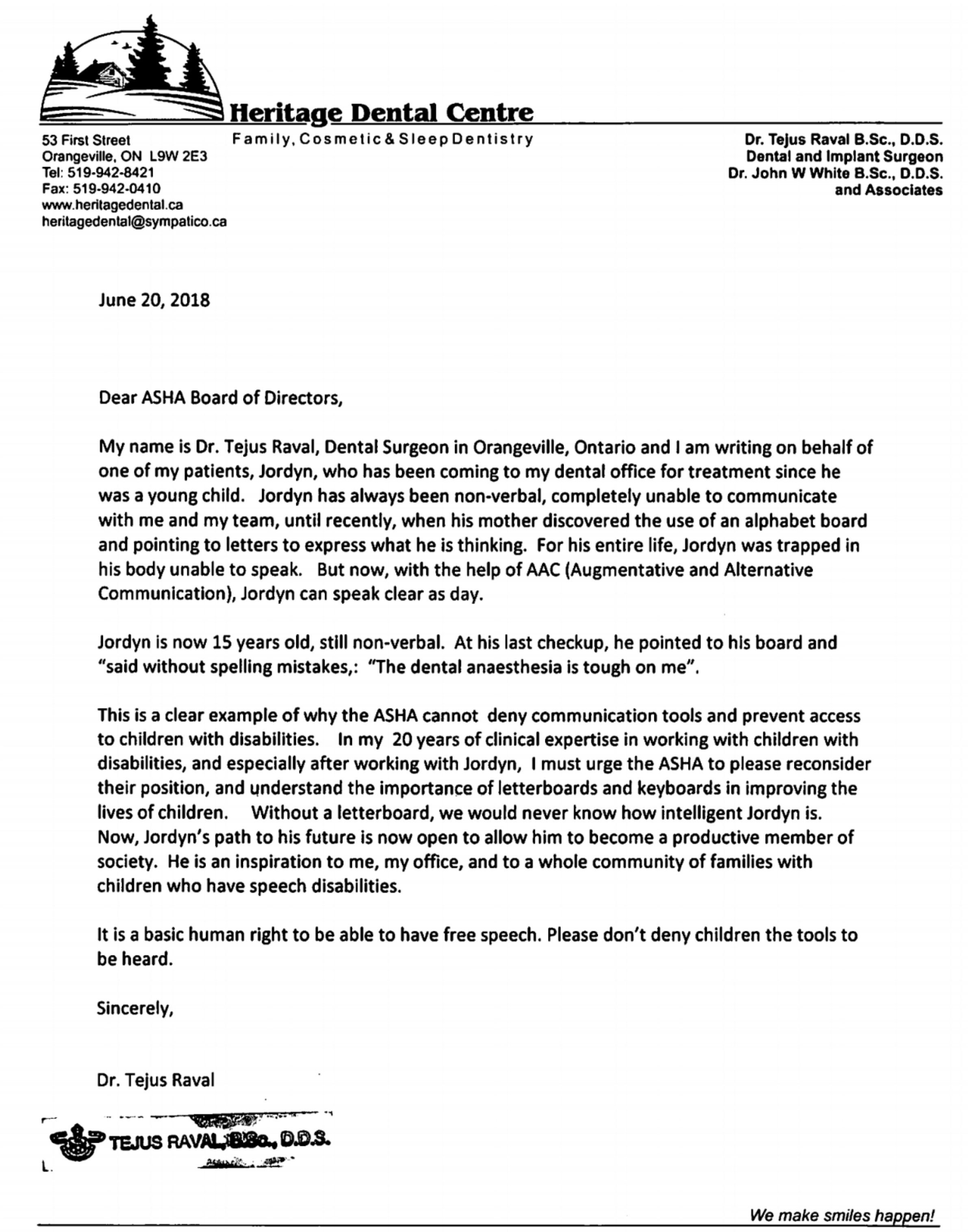
I urge ASHA to withdraw these proposed statements, and should you deem it necessary, conduct a careful and unbiased examination of all the viewpoints.

From my viewpoint as a parent, and my son's viewpoint as a client, we believe these modalities are the answer for so many with sensory motor differences that are locked inside with no way to express themselves. As a parent, I am careful to ensure that my son's communication (by his chosen method) is his own, and find it insulting that anyone would think I would allow anything other than that. Trust your clientele – parents and the people with the disabilities – to guide you to what may be the next innovation in "Making effective communication, a human right, accessible and achievable for all."

Sincerely,

Kelli Pallett, M.Sc, P.Eng.
Mono, Ontario, Canada

Cc: ASHA Board of Ethics
ASHA Governance



Heritage Dental Centre
Family, Cosmetic & Sleep Dentistry

53 First Street
Orangeville, ON L9W 2E3
Tel: 519-942-8421
Fax: 519-942-0410
www.heritagedental.ca
heritagedental@sympatico.ca

Dr. Tejus Raval B.Sc., D.D.S.
Dental and Implant Surgeon
Dr. John W White B.Sc., D.D.S.
and Associates

June 20, 2018

Dear ASHA Board of Directors,

My name is Dr. Tejus Raval, Dental Surgeon in Orangeville, Ontario and I am writing on behalf of one of my patients, Jordyn, who has been coming to my dental office for treatment since he was a young child. Jordyn has always been non-verbal, completely unable to communicate with me and my team, until recently, when his mother discovered the use of an alphabet board and pointing to letters to express what he is thinking. For his entire life, Jordyn was trapped in his body unable to speak. But now, with the help of AAC (Augmentative and Alternative Communication), Jordyn can speak clear as day.

Jordyn is now 15 years old, still non-verbal. At his last checkup, he pointed to his board and "said without spelling mistakes,: "The dental anaesthesia is tough on me".

This is a clear example of why the ASHA cannot deny communication tools and prevent access to children with disabilities. In my 20 years of clinical expertise in working with children with disabilities, and especially after working with Jordyn, I must urge the ASHA to please reconsider their position, and understand the importance of letterboards and keyboards in improving the lives of children. Without a letterboard, we would never know how intelligent Jordyn is. Now, Jordyn's path to his future is now open to allow him to become a productive member of society. He is an inspiration to me, my office, and to a whole community of families with children who have speech disabilities.

It is a basic human right to be able to have free speech. Please don't deny children the tools to be heard.

Sincerely,

Dr. Tejus Raval

TEJUS RAVAL, B.Sc., D.D.S.

We make smiles happen!

June 20, 2018

Michael Pallett

michael@pallettcorner.ne

To: Board of Directors

I am responding the Draft ASHA Position Statement dated May 24th, 2018

My name is Michael Pallett, father of a 15-year-old autistic boy.

For over 10 years my wife and I investigated and submitted my son to various interventions aimed to improve his ability to communicate. Many of these interventions were attempting to help him develop oral communications skills. Speech and Language Pathologists were among this group.

Few of those interventions produced any significant results. We were always left trying to justify the time and cost, against a hopeful expectation that these efforts were producing some benefit; that we were just unable to see or measure.

When my son was 12, we visited HALO. Since then both my wife and I have worked with my son using RPM principles initially taught to us by Soma in Austin.

The impact has been significant, and far more visible and tangible than other interventions we have undertaken with our son. It has changed the course of his life, and ours as well.

Even if you discount earlier communication as being potentially influenced by ourselves (after all what parent does not influence their child's communication when they are just learning). What cannot be discounted is the richness and fullness that he is experiencing in his life because of this effort. What cannot be discounted is his independent writing using a keyboard. His independent assertion that until we started with RPM, his future was limited to a tiny spoken vocabulary expressing immediate needs and video's intended for toddlers.

It was not predictable that he would be rock climbing with active coaching from others who do not communicate with a letter board. It was not predictable that he would develop a romantic relationship with a wonderful girl that communicates similarly - both of whom have expressed their feeling publicly about each other (in writing). It was not predictable that he would have friends that would gather and celebrate their ability to socialize and play games together. Nor was it predictable, the noticeable increase in physical control that he experiences; to which both my wife and I (who attend him constantly) can attest.

With all due respect to industry experts, most of them get to go home at night and don't stay up worrying about their own child's future as an autistic. Most don’t worry about after they are gone, financing their child’s support beyond their lifetime. They simply cannot achieve the same level of observation that parents experience week in and week out. All of this is evidence. Eye witness evidence. Evidence that we can and will testify to. It may not be a double blind controlled study. But your statement will effectively eliminate, or certainly hamper the potential for that research and the gathering of data that is needed for objective experts to form an informed opinion. This becomes a catch 22 for this population.

In the meantime, your statement will not directly affect our son. We already know with 100% certainty that this position is misguided. But it is a great disappointment that your position will effectively remove this method as an option for so many. It is more than a disappointment in ASHA as an organization. Because, when I think that had you published this a few years ago, I as a parent might have believed you. And that would have denied my son and my family the wonderful experiences that have followed. In this context, what I feel is more akin to anger for that which might have been taken away, and sadness for those who will never have the opportunity.

If ASHA cannot support this intervention, ASHA could remain silent. Silent, or better yet, ASHA could actively seek the data that they need to support this modality through ASHAs own studies. ASHAs statement will close the door for many. ASHA may argue that to not take a position is paramount to causing harm for cases where these methods are used by inexperienced or fraudulent individuals who might attempt to lay claim to a non-speaking persons voice. I cannot claim this has never happened. But I am also aware of the much greater harm that is done by restricting access to tools that non-speaking people could potentially use to communicate. The solution is not to disavow, but to explore with optimism the many success stories and determine how those successes could be made more widely available in a responsible way, to better protect clients from the inexperienced or fraudulent.

Should ASHA publish this position statement, it will be hard for ASHA to later reverse this position. Yet as more families successfully utilize these teaching techniques, and more children start to establish any measure of independent communication, the pressure will mount for ASHA to reconsider. There are multiple documentaries screening now that illustrate success stories (including at least one internationally recognized award-winning documentary). As these and other films that are under consideration make their way into the main stream, the incongruity between what people see and experience will starkly contrast with the ASHA position. Reconciliation as evidence mounts will be expected.

Given my experience with parents of autistic children, who struggle daily to find effective easements to the challenges they live with continuously, and the passion that can be generated from that momma bear well of emotion, I would expect that ASHAs disclaimer would be ineffective:

> "Disclaimer: The American Speech-Language-Hearing Association disclaims any liability to any party for the accuracy, completeness, or availability of these documents, or for any damages arising out of the use of the documents and any information they contain."

This one-sided disclaimer seems a paltry defence should a court be asked to examine the positive evidence that exists today, to support the efficacy of these teaching techniques in many instances. Especially where there are multiple autistic people, who actively advocate for these techniques, who have now achieved independent typing, and can communicate in public, and could testify in a court of law. It is easy to find evidence to support a preconceived belief if you go looking for it. Just as this ad hoc committee can assemble evidence for a position, others can assemble evidence for a contrary position. The comparison of old studies verses active heart wrenching live testimony from real disabled people demonstrating a previously unimaginable ability to communicate before a jury would be compelling. I for one would be very interested in any class action suit brought against ASHA in the future. I suspect my son and others would be eager to testify and have that platform from which to publicly advocate for themselves.

In my opinion, and based on my first-hand experience, this position statement does damage to a vulnerable community your organization is supposed to support. I urge you to reconsider its publication.

Regards,

Michael Pallett, B.SC

Mono, Ontario, Canada

Cc: ASHA Contact Action Center

ASHA Board of Ethics

ASHA Governance

June 24, 2018

Sandra McClennen

sandi@mcclennen.us

To ASHA Board of Directors and Members:

I am a psychologist who has used facilitated communication with some of my clients in order to communicate to make therapy effective. I have been trained in good technique as a facilitator and am always careful to get independent confirmation of any communication that might change lives.

Here are a few examples of communication that have resulted in measurable changes in my clients' lives:

1. A client who was having meltdowns that were not typical for her typed that her mouth hurt. Her mother took her to their dentist. She needed a root canal. The meltdowns stopped.

2. A client who had been hitting his head against walls for years and wore a helmet for protection, and for whom behavioral therapy did not stop the head-hitting, told me that his stomach hurt most of the time. His mother found a physician who took this seriously and determined that he needed a gluten-free diet. My client cooperated fully with his mother, and his head-hitting slowed and ceased. I used cognitive behavioral therapy with him as, having communication, we could have conversations. He has been helmet-free for many years.

3. A client who had a few words always asked for a hamburger when his family went to restaurants. They ordered it for him, and he had a meltdown. They showed him a picture menu, he pointed to a hamburger, they ordered it, and he had a meltdown. These necessitated one

parent removing him while the rest ate or everyone leaving. With facilitated communication, I asked him what he really wanted. He told me “French fries.” His mother took him to a restaurant after our session. He said “hamburger” but she ordered French fries. He ate them happily, and the family has been able to eat out since.

4. A client whose school considers him at a beginning level of literacy but whom I have found to be very intelligent wanted to go to college (at age 19). He worked very hard on independent pointing for multiple choice exams with 4 options and has now taken three college classes.

For all these clients and many others, no other communication system was effective and parents had to guess what their child wanted. All had been receiving services from a S/LP through school and sometimes privately in addition. None had interactive communication.

I shudder to think of how much less fulfilling these people’s lives would be without communication.

It is inconceivable to me that ASHA’s Ad Hoc Committee refuses to consider input or evidence from people whose lives have become so much more fulfilled by having communication, through facilitated communication when nothing else worked for them, and refuses to consider input or evidence from ASHA members with experience in facilitated communication and RPM.

Further, a policy decision that bans practitioners from using a specific communication method (rather than invoking an individual S/LP’s judgement as is currently the case) should involve a careful and unbiased examination of viewpoints. Instead, ASHA’s Ad Hoc Committee is comprised of individuals with histories of personally attacking and making disparaging remarks about facilitated communication and RPM and even about individuals with disabilities who use these methodologies.

I THEREFORE REQUEST that ASHA withdraw the proposed statements and issue a formal apology for the damage that has already been done to the civil rights of individuals with disabilities by the Ad Hoc Committee.

Sandra McClennen, Ph.D.
Psychologist

June 24, 2018

Charlene Brandl

crbrandl777@gmail.com

Dear Friends at ASHA:

I am a retired special educator, now working with adults who use various forms of typing as their primary means of communication. Nearly 30 years ago, I was introduced to Facilitated Communication while teaching at the elementary level. Your stated motto: "Making effective communication, a human right, accessible and achievable for all" describes exactly what a difference FC has made in the lives of so many of the non-speaking people of all ages with whom I have worked.

Sign language, PECS, various AAC devices were tried along the way, but for these folks, only typing has been effective. Without exception, if we can find something that works, their lives are forever changed for the better. Young students were able to be fully included in regular classrooms, older students have gone on to college, and once out of school, the adults I now serve are able to tell their support team what they want in their lives in the way of home, work, and community involvement. Absolutely nothing I had tried before ever made such a difference, nor did the other methods allow such full participation in life.

If you are looking for evidence of effectiveness, I invite you to come and meet some of these amazing people, who - until typing became a part of their lives - were terribly underestimated and misunderstood. Many had been seen as cognitively disabled, and/or presenting significant behavior challenges. Typing opened a whole new world, and many of the problems disappeared. Most of them continue to struggle with neuro-motor difficulties and so some level of physical support is needed, but they can and do learn, and they DO have much to say.

I have seen first-hand how devastating it is if an effective means of communication is no longer available to an individual for some reason. We do NOT want that to happen to these folks. They deserve our full support.

Please withdraw the proposed statements rejecting both Facilitated Communication and Rapid Prompting immediately, and then look for ways that your organization might encourage efforts to make typing accessible to all who might benefit from this method of communication.

Thank you for your consideration.

Respectfully,

Char Brandl

June 25, 2018

Brent Sullivan and Diane Belnavis

https://juniperhillfarms.org/2018/06/25/an-open-letter-to-asha-advocating-for-the-right-to-a-communication-method-of-choice/

To the ASHA Board,

This is a response to the ASHA committee’s statement regarding the use of RPM as a teaching and communication method.

I am the founder of a farm which has been home to five men with autism for eight years. For 40 years I have worked in the disability field, the last fifteen specifically in housing for adults wishing to live independently. My family member, Brent, has been spelling on a letterboard for four years. He has little spoken language. He joined our family 30 years ago at the age of 18.

At 49 years old, Brent has a perspective on life that is different from his younger autistic non-speaking peers. He has been out of the education system for 30 years. Until four years ago, I believed that I had provided him with a fulfilling life of his 'choice'. I now know that he is a poet, and a lover of math and science who wants a full academic education. He wants a loving relationship with a female partner. He wants what society considers a full life.

For him, spelling has not only been life-changing, but also life-saving. Two years ago, he spelled 'STOP I AM IN NEED OF MEDICAL ATTENTION'. He described his symptoms, of which we were completely unaware. He was subsequently diagnosed with testicular cancer. Since then he has undergone surgery and regular medical exams with blood tests, Cat scans and X-Rays.

Below are his words, after being declared 'cancer free'.

MY DESIRE IS TO ADVOCATE FOR COMMUNICATION SUPPORTS AND HOUSING FOR ADULT AUTISTICS. LIFE IS WORTH LIVING NOW THAT I HAVE COMMUNICATION. COMMUNICATION JUST SAVED MY LIFE. I FEEL GRATEFUL BECAUSE I TOLD MY DOCTORS WHAT WAS HAPPENING.

I AM THE MOST LUCKY MAN EVER. BUT THE ONES IN SILENCE ARE NOT SO LUCKY. THEY MIGHT NOT EVER BE ABLE TO TELL SOMEONE THEY ARE SICK. THEY MAY NEVER SAY I LOVE YOU.

I NEED TO MAKE SOMETHING OF MY TIME ON EARTH. THE WORST THING IS TO BE A VISITOR TO LIFE INSTEAD OF A PARTICIPANT. I WANT TO ADVOCATE FOR OTHER INDIVIDUALS WHO ARE TRAPPED IN THEIR OWN BODIES. THEY MUST FEEL THE SAME LONELINESS I DID. TIME TO JOIN THE CONVERSATION INSTEAD OF BEING THE CONVERSATION.

THE SAD REALITY IS THAT MANY HAVE GIVEN UP ON ADULTS. OUR LIVES MATTER. THIS IS MY MISSION NOW. THE ADULTS HAVE GONE SILENT TOO LONG. MY QUALITY OF LIFE HAS CHANGED DRAMATICALLY SINCE I STARTED SPELLING .

NOT WITHOUT SPELLING WOULD I HAVE BEEN ABLE TO GET THE MEDICAL HELP I NEEDED. JUST HOW MANY HAVE DIED OR SUFFERED JUST BECAUSE THEIR OWN BROKEN BODIES CONDEMN THEM TO SILENCE?

THERE IS MUCH WE NEED TO DO. LET'S REACH OUT TO SILENT ADULTS AND TEACH THEM TO SPELL ON THE LETTERBOARDS. TEACH PARENTS, CAREGIVERS AND THOSE WHO WORK WITH MENTAL EDUCATION THAT ONE IS NEVER TOO OLD TO LEARN.

We respectfully ask you to consider withdrawing your statement on RPM.

Sincerely,

Diane Belnavis

June 24, 2018

Dr Sanda Bonchis
Mount Ommaney QLD 4074
AUSTRALIA

abonchis@bigpond.net.au

Heather Bupp, Esq. Ex Officio Board of Ethics American Speech-Language-Hearing Association

Dear Mrs Bupp,

PRESERVE COMMUNICATION CHOICE

It has come to my attention that a reputed organisation such as the American Speech-Language-Hearing-Association (ASHA) has set up a committee that plans to deny some communication choices and access for children and adults with complex communications needs. I am concerned that by rejecting the Facilitated communication as a choice of communication, you would be breaching a fundamental right of communication for some individuals who have no other choice.

I am Dr Sanda Bonchis MBBS, Fellow of Royal Australian College of General Practitioners and mother of a 20 years old who is at risk of loosing his voice if the committee proposal goes ahead. I have been a doctor for almost 30 years and as such I understand well the "evidence based practice" scenario. My son was diagnosed at the time when the concept of regressive autism was relatively new. At the time he was still able to use a mouse to play computer games, to colour in and eat by himself. We have started intensive ABA therapy and he started using PECS for communication and attending Autism Queensland classes. For reasons that still elude all the specialists and myself, his physical abilities continued to regress. Over the years he developed Severe Dyspraxia/Verbal Apraxia and his ability "to control his broken body" have significantly eroded. As he regressed during the time of ABA and Autism Queensland intervention, I have been asked to withdraw him from the Autism Queensland as "he had made no progress" and even "forgot" how to use his PECS. At that time, we were lucky and came across the concept of Facilitated Communication (FC) Training. Needless to say, that at first both me and my husband who has a PhD in Engineering were rather sceptic.

We knew our kid before regression met all his developmental milestones and was able during the ABA to give the correct answer independently to simple maths, ahead of his peers, so we assumed he was still clever but still sceptic about the quick way he learned to type. The eye-opening moment came shortly after starting FC, during a speech therapy session when he was asked who is mum and the answer "the lady at home carrying boxes". The therapist asked me "Aren't you a doctor?". I smiled and shrugged my shoulders, only to find myself that night, like every other nights carrying my paperwork from office in boxes. It is then I knew only my boy could be the author of such candid description. After that we never looked back, and our lives changed dramatically for the better.

The boy, whom in Autism Queensland's Teacher point of view was too delayed to be educated, managed to finish Grade 12 in a regular school with great results and he had been accepted at University. After all, even sceptics were left speechless once they realised his keen interest to learn and his quirky sense of humour. No way a non-verbal, forever on the move child would stay still and listen in in Modern History or Chemistry, unless he was interested in the subject. Now that he is an adult and out of school, he is fighting to get some control of his body /dyspraxia and is able to type with a simple finger touch at the elbow or pulling of his shirt sleeve above the elbow. I am looking forward to him one day being able to "have a voice" by independent typing.

I know that nothing would stop us using FC with our son and we were lucky to meet therapists, teachers and lawyers who were prepared to learn about my son's ideas and plans for his life and help him along. He is a keen traveller and we hope one day he will manage to live a semi-independent life, choose and manage his own support workers.

As a mum I know that I will always fight for my child's best interests, but as a doctor it is my duty to fight for the other kids or adults with complex communication needs, too. At work every day I see kids being prescribed medication for anxiety, ADHD, OCD, PNDD and in those with Autism with meltdowns, self-harming, head banging powerful antipsychotic medication. The "behaviours" considered as part of severe autism, more often than not, are due to pain or frustration due to lack of communication. The medicines only control partly the problem and if we could find out what truly bothers the child by giving them the gift of a "voice" we could find out that often the needs are not just food and sleep. Addressing their concerns works a treat and in my son's case once he mastered expressing his worries through FC we became "drug free" and almost meltdown free. He is a content, cheerful young man with emotional maturity to accept his situation. If there is a glimmer of hope that others could have their lives enriched like my son's has been by learning to communicate I urge you to be open minded and fair and listen to all parties opinions, not just a biased committee made up by anti FC members. Already the effects of lobbying against FC training has likely deprived some children and adults of reaching their potential.

I hope you will give this submission careful consideration.

Yours sincerely,

Dr. Sanda Gabriela Bonchis

CC: Martha Moore, ASHA Governance

Action Alert AHSA

June 24, 2018

Tyaska Ensdorff

ty.ensdorff@gmail.com

To all it may concern,

Thousands of years ago, smoke signals and drums were used as a very recognized mode of communication. Though simple, these ways to connect evolved, over the centuries, into the tinder that sparked many groups and individuals to fight for their own ways to communicate, but unfortunately, even with those many great fights for human rights and acceptance, our ancestors' fundamental struggle continues to this day. This is for many reasons and for many people, but right here and right now, it is because of you. You would think this would not be the case though, right? You *are* the American Speech-*Language*-Hearing Association. it is a little hypocritical, especially with a mission like yours.

Invalidating RPM as a real way to communicate for non-speaking (disabled) people is unjust, immoral, incorrect, and should not be done, as if you do, so many worthy, non-speaking people will be wrongfully plunged (back) into deafening silence. And, through taking your position, you are choosing to install cultural assimilation and to uphold discrimination and distrust and it is extremely disheartening that a group that has such a power to do good, in this regard, is even thinking of being so prejudiced and closed minded. RPM has been so freeing and positive to *everyone* that I have heard from and experienced it with, and I think you might want to do more "research" on that rather than jumping the inequitable gun and assuming things because you are too bigoted to actually go out and observe it before making such a serious proposition.

Do not let the unimportant matter of politics and personal gain get in the way of real people's well-being (speaking or not), as I could only imagine that for a large organization like yours, the individual needs and well-being of those you so called, "serve" *are* unimportant. Thus, it makes sense why a small minority group of non-speaking simpletons, as you people see them, are as unimportant as our bickering about something awfully important. This is more than you. This is more than me. This is about the basic human right to communicate. And it is an awful shame to even have to point that out to you all. I am disappointed beyond words that you would let a one-sided personal prejudice get in the way of that.

Have you ever even watched somebody do RPM in person? Judging by your position statement you did a basic google scholar search and called it good. What an audacity you all have to write off people's livelihoods and intelligence just-like-that. Autism is a disability protected under the ADA, (who you failed to consider *again*) and it is a federal crime to treat any disabled person any less favorably than a normal one, let alone take away their voice. I mean RPM is used by *human beings* with *real* intellectual ability that are only disabled of their bodies. I know that your meaningless and immoral Ad Hoc committee does not see it that way, but it is true nonetheless.

Here are the results from *my* basic search. It really is not that hard to find that the *one* study that exists about RPM has found that, "...individuals who went through RPM engaged in fewer repetitive behaviors and were more focused"(Stout 8). And that the resemblance to FC is beyond too distant in process and outcome to base any judgement on in regards to RPM. "FC involves a therapist (or facilitator) supporting the hand of a person with autism while a message is typed on a letter board"(Tostanoski, Lang, Raulston, Carnett, David). We All know this. *And* most agree that FC was, and is, unethical and undisputedly Pseudoscientific based on many conducted studies. RPM is entirely different, though, because of one key difference you all failed to understand! When using RPM, ”...people with autism point to letters on a letterboard in order to spell out words”(Stout 5). The key word here is the *point*. With RPM, there is absolutely no gesturing, guiding, or influencing bias like with FC. The parent, therapist, or facilitator holds the board and verbally prompts and encourages the non speaking person to communicate. There is no personal bias here, except for ASHA’s, and no interference with the words that come out of RPM as it does not use physical touch or modification and, thus, does not have any potential to be influenced by the facilitator like FC.

I have seen, first hand, the way that RPM changes lives and how it gives the gift of *real* independant conversation and connection. I am a speaking, non-autistic person, just like you, and I cannot believe how you do not see it in the same way. I have volunteered and worked with autistic adults and children and seen both use RPM and other similar assistive technologies in person. It really is incredible to see when their ability to communicate *for themselves* is unlocked. Think of Stephen Hawking. His disabled body did not match his brilliant mind and thus his assistive technology was undeniably positive and helpful in communication. How is RPM any different? I can personally attest that RPM is a legitimate way that non-speaking people use to communicate their own thoughts! It should not matter that the boards need to be held up, or whatever your unrealistic and unlogical problem is.

I have done RPM with my amazingly intelligent and poetic autistic cousin and, again, can verify that it is all her. I just held up the board. *That is it*. I did not physically guide or influence my cousin to touch any letters in any way while doing RPM. I just verbally encouraged her to keep going and to stay focused. So, because of this, I cannot stress enough that, even with its similarities, RPM is nothing like FC in outcome and process. Also, my family, and multiple others, have video after video documenting RPM in action. It is not some grand scheme or trick. It is real intelligence, thought, and opinion coming through just in a different way than normal.

Again, you have the opportunity to make things right! You can be the next unjust and dogmatic “haves” against the supposedly weak “have nots”. You can be the bad guy in this story. Your beloved ASHA could go down in history for repeating it, and ruining and spitting on the acceptance, independence, growth, and well-being of a federally protected minority group, as you and so many other villains have done in the past. Or, you can be a hero and can give us a chance and let non-speaking people from all walks of life have a shot at that acceptance, independence and the communication techniques that are so rightfully theirs to use.

So yet again, I urge you all to open your closed minds and see and understand that people who do not orally communicate, are still intelligent and are capable of having sound and genius minds. Unlike FC, RPM is a tool that allows them to unlock and express that great potential. Autistic people *are not* vegetables, even though you may see them that way, and they have an unconquerable voice and capable mind inside them. Do not be mistaken! RPM is a valid and wonderful thing, and could *not* bring harm, but instead brings opportunity and is a step to independence for non-speaking people to communicate their own thoughts, again, not the “facilitator’s”. As I said, it is a necessary and important step for non-speaking people in their never ending struggle to communicate and prove themselves as able, as they are otherwise seen by people like you as incapable of such. *They* need this, and *you* need to respect that, and them. do not be responsible for ruining the great communication technique that is RPM.

Thank you for your time and giving the public opportunity to respond to your position.

Sincerely,

Tyaska Ensdorff

ty.ensdorff@gmail.com

June 24, 2018

[REDACTED]

Ladies and Gentlemen,

This letter is in response to your Ad Hoc Committee on Facilitated Communication (FC) and Rapid Prompting Method (RPM). After reading the draft statements on Facilitated Communication and Rapid Prompting method we find both statements restrictive and all encompassing. <u>These position statements will have a chilling effect on how disabled people are treated in schools and supported in their community.</u> These position statements are also out of step with the possibilities offered by new technology and changes in how disability is viewed and treated in society. My views are base on the following points:

1. Our son is on the Autism Spectrum and non-verbal. All through his school years a zealous speech language person made it her business to dissuade teachers and school administrators from the use of Facilitated Communication. Consequently, we received little cooperation and our son got very little benefit from his school experience. We, his parents, taught him to write and do mathematics. Incidentally, our son is taking classes at the local junior college with an aid and Facilitated Communication**. <u>Think of the harm your position statements have done and could do in the future!</u>**

2. Your draft position statement talks about human rights. Why should your organization and those who subscribe to your opinions make choices for a disabled person and their family? Why should your organization work so hard to discredit Facilitated Communication and Rapid Prompting Method when the disabled person and family chose to use these methods? The Americans With Disabilities Act (ADA) clearly states who decides which aid or service is needed<u>. *"When choosing an aid or service, title II entities (State and local Governments) are* **required** *to give primary consideration to the choice of aid or service requested by the person who has a communication disability."*</u> **(REFERENCE: https://www.ada.gov/effective-comm.htm)**

   A. There is a risk that Facilitated Communication and Rapid Prompting Method can be influenced by the person assisting the disabled person. If the disabled person and their family acknowledged the risk of influence and make efforts to reduce or eliminate this risk to communication, it is reasonable for them to use Facilitated

Communication or Rapid Prompting Method. Any denial or manipulation based on the possibility of influence of communication, is a violation of the disabled person's civil rights protected by the ADA.

B. There have been false accusations of sexual assault as a result of Facilitated Communication in the past. Unfortunately, humans have a propensity to tell untruths in the non-disabled world and the disabled world. A recent false rape case in Connecticut make this point vividly. (REFFERENCE: https://www.ctpost.com/news/article/Yovino-pleads-guilty-in-false-rape-case-12969059.php) Again if the disabled person and family acknowledge the risk of false statements and make provisions for that possibility, their chose to use Facilitated Communication or Rapid Prompting Method must be honored. Any denial or manipulation based on the possibility of a false accusation, is a violation of the disabled persons civil rights protected by the ADA.

3. Your draft position statement on Facilitated Communication questions, authorship and validity of this communication technique.

A. Your position paper makes the claim that there is a lack of scientific studies that validate Facilitated Communications. This is a false misleading statement. There are studies that support the validity of Facilitated Communications. You could say you disagree with these studies and explain your reasoning but failing to acknowledge them is intellectually dishonest and not worthy of your organization. Why not allow your members to explore all the studies and form their own opinion?

(REFFERENCE: Research Supporting Authorship http://soe.syr.edu/media/documents/2011/6/Research_Supporting_Authorship_version_22.pdf)

B. The world, society, technology and science are evolving rapidly. Sue Rubin, Jamie Burke and DJ Savarese are non-verbal and on the autism spectrum. Each one of these disabled people graduated from college in recent years and all have used Facilitated Communications. **How is it possible for these people to learn to communicate and graduate from college if what you are claiming in your position paper is true? Their very presence and accomplishments contradict the claims made in your position paper.**

It would be hoped that an organization like yours would focus on the future and trying to empower people with disabilities. By trying to stamp out a communication practice that shows promise; versus trying to understand why it is working you are failing the community you serve and risking becoming redundant.

[REDACTED]

C. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5919599/

June 24, 2018

[REDACTED]

"I am writing to you today as the parent of a non-speaking 18 year old individual. The purpose of my letter is to urge you to withdraw your draft ASHA Position Statement on Rapid Prompting Method dated May 24, 2018. This Statement has the potential to cause (and may have already caused) people who spell, type or write to communicate to lose access to their preferred and most effective means of communication. This Statement is in direct opposition to AHSA's vision of "Making effective communication, a human right, accessible and achievable for all."

My daughter (who I will refer to as "AN") was diagnosed with autism and apraxia as a young child. As her mother, I made a vow that I would leave no stone unturned in an effort to help her achieve the greatest possible quality of life. I began by following every recommendation I received from the various professionals who became involved in our family's life, including speech therapists, occupational therapists, physical therapists, special educators, behavior analysts, psychologists and therapeutic staff support. AN received services at home (starting at age 1) as well as at school throughout her elementary and middle school years. At the age of four, she was placed in an intensive educational, behavioral and therapeutic program due to a lack of progress in her development, particularly receptive and expressive language. She remained in that program until the age of nine, when she transferred to another specialized, behavior-based school setting recommended by our local school district.

After thirteen years of speech therapy with several different speech language pathologists (SLPs) in various settings, AN still lacked any functional communication at the age of fourteen. She had been taught by certified SLPs using most of the tools and techniques promoted by ASHA, including picture communication boards, sign language, and speech generating devices. Her school practiced ABA-based Verbal Behavior in an attempt to integrate communication goals into all parts of AN's day at school. Not one of those tools or techniques succeeded in helping AN develop any meaningful communication.

As you might imagine, entering adolescence without any way to express herself, AN's aggressive and self-injurious behaviors escalated and she continued to make little to no progress on any of her goals, speech-language related or other functional skills. It was at that point that I decided to venture into alternatives to the standard therapies and educational approaches that were being offered. I figured we had nothing to lose, because at that point all the recommended, "evidence-based" therapies and interventions had failed my child.

The alternative I decided to pursue was RPM. To be honest, at first I was incredulous to think that my daughter could understand the information being presented to her in her first RPM sessions. I had been conditioned to believe that she was still struggling to understand even basic language or to identify and know the function and sounds of letters, much less be able to spell words. However, I was willing to give it a chance because all else had failed up to that point. It was suggested by the RPM provider that we treat AN's disability as a lack of motor skill rather than a lack of cognitive skill. After a few days, we returned home and began practicing what we had been taught.

Fast forward almost four years to today. AN is able to type her wants, needs, hopes, dreams, likes, dislikes, political opinions, scientific fact, original poems and anything else on her mind without prompting or physical support. She does still require a communication partner to help her regulate her body and keep focus on what she is spelling or typing, but there is absolutely no translation or interpretation to be made. AN's typed communications are undeniably and indisputably her own. Ask anyone who has met her.

AN's breakthrough in communication has enabled her to fully participate in her own life and make decisions for herself. Her behavioral outbursts have diminished to almost non-existence, and when they do occur, she is able to communicate what is the problem and regain self-control within a very short period of time (less than a minute). She was able to successfully transition from the most restrictive educational environment (full-time placement in a segregated, specialized school) to the least restrictive (included with typical peers in regular education classes). She is enrolled in the local community college. She participates in doctor appointments and makes decisions regarding her care. She expresses about her concerns about the environment and about civil rights. She shares her plans for her future. She participates in family life and develops deep and meaningful relationships with her loved ones because they are able to get to know her inner thoughts.

Without having had access to RPM and open-minded professionals, AN would in all likelihood still be injuring herself in frustration. Her progress over the last four years can only be attributed to the paradigm shift that occurred when we began teaching AN motor skills to point to letters on a letter board (and later a keyboard) and engaging her mind with age-appropriate lessons on a wide variety of topics. Only after the previous "evidence-based" approaches were abandoned and the alternative, unproven approach was incorporated did AN develop the ability to use language to express herself.

Adoption of ASHA's draft position statement would serve to do the opposite of what it claims. It would *deny* non-speaking or minimally speaking people the communication rights of autonomy and freedom of expression. Rather than attempting to shut down the use of a method that has thousands of families providing anecdotal evidence of dramatic, life-changing success for their non-speaking loved ones, ASHA should be attempting to learn from those families' experiences. ASHA should be listening to the non-speakers who have reached their goal of independent typing about their experiences, regardless of the method they used to achieve that goal. ASHA should be working to scientifically validate the principles of RPM and other non-traditional methods so that your organization's vision of "making effective communication, a human right, accessible and achievable for all" can be fulfilled."

June 24, 2018

Jennifer Rainey

Dear ASHA Board Members,

I am the mother of a 12-year old non-speaking boy who has autism and apraxia and am writing to inform you of my serious concerns about the ASHA position statement regarding Rapid Prompting Method. My son was diagnosed with autism at the age of 18 months and was immediately enrolled in early intervention programming, including weekly speech therapy sessions (both individual and group). After a year of these services, he had still made almost no progress in his functional communication skills and I sought additional weekly therapy with a private speech therapist. From the ages of 3-9, my son received approximately 1-2 hours of speech therapy per week and countless additional hours of reinforcement at home.

During these years of speech therapy, my son was exposed to a number of traditional approaches including ABA, PECS, and an AAC device. With PECS, my son was able to start making some basic requests for food and I was encouraged at this first glimpse of communication. Spurred by this initial success, I signed up for a training course in PECS where I learned in great detail alongside speech therapists, educators, and other professionals how to implement this method step by step. For 9 months, we diligently worked on these skills both in speech therapy sessions and at home. By the end of this time period, my son was never able to communicate more than just basic requests for food or activities from a preselected group of choices. He was never able to express a feeling or thought and never able to communicate an original idea.

After months of having reached a plateau with PECS and with the agreement of my son's SLP, we decided to try an AAC device. Specifically, my son got an iPad with the LAMP Words for Life app. As with PECS, I took training directly from the creators of LAMP alongside SLPs and other professionals. In fact, I had more training specifically in the use of LAMP than my son's SLP. I also trained his team of play therapy volunteers to use LAMP with him, so he was getting a total of 10-20 hours per week working on these skills. Still, after another year of working on communication in this intense manner, my son had an expressive vocabulary of only 25 words on his device consisting solely of basic nouns and verbs.

Finally, when my son was nine years old, we learned about Rapid Prompting Method. I was skeptical at first because we had tried so many other things to help him communicate, but I decided to take a leap of faith to give him every opportunity possible to gain meaningful communication and I am so grateful that I did. As with PECS and LAMP, I educated myself on RPM so I could implement it at home instead of relying solely on our speech therapy time to help him progress. It quickly became apparent that spelling was the key to unlocking my son's communication. I had never seen him so highly focused and determined with any other method of communication. As his communication abilities grew, his frustration and self-injurious behaviors decreased. Now, three years later, he is able to fully communicate his wants, needs, feelings, and thoughts.

While the ad hoc committee's statement against RPM states that spending time on RPM may cause lost opportunity to access other "evidence-based" interventions, in my son's case the exact opposite happened. After years of time, money, and energy spent on the methods that ASHA supports, our son finally found his voice thanks to a letterboard and now this proposal threatens to undermine that.

Having had training in PECS, LAMP, and RPM, I fail to understand how the ad hoc committee has come to the conclusion that RPM is somehow, "not consistent with the communication rights of autonomy and freedom of expression and prevents access to the person's human right of communication". With both PECS and LAMP, my son only ever had the opportunity to communicate from a preselected vocabulary based upon our assumptions of what he wanted to say. His SLP and/or I were determining what vocabulary was made available to him and when as we worked to increase his communication skills. With RPM, his options are limitless because if he can spell a word, he can use that word whether or not it is one that has been printed on a picture card or programmed into a device by other people who think that they know what he wants to talk about. I will never forget how hard that realization hit me the day that he told me he wants to visit Stonehenge. Never in a million years would I have created a picture card for Stonehenge or programmed it into his iPad and this is when it dawned on me that perhaps the reason those methods were so unsuccessful for him was because he never had access to what he really wanted to say.

Additionally, my son has gone from being unable to be assessed academically to being able to complete the full range of academic testing for his special education evaluation. This past fall, the school psychologist was able to complete testing with my son and he tested above grade level in reading comprehension and spelling and at grade level in mathematics. Following the completion of testing, the school psychologist revealed to me that she was actively watching for signs of my influence on his testing, but saw none and considered his scores to be a valid representation of his abilities.

I am appalled at the damage that has already been done and by that yet to come if this statement is made into policy. Children like my son will have the validity of their communication questioned and opportunities removed from them. Worse yet, there are children out there just waiting for someone to help them find the thing that will finally let them be heard and they will never have the chance. By dismissing the use of RPM and similar methods, ASHA would be denying this most basic human right of communication to thousands of people, which is in direct conflict with your motto.

It is my understanding that the ad hoc committee refused to consider input or evidence from those who use these means of communication and from ASHA members with experience with these methodologies before creating this proposal. It is incredibly concerning to me that this committee has deemed it reasonable to exclude those who are most well-informed of these methods from the conversation regarding their efficacy. I am requesting that ASHA withdraws the proposed statements and issues a formal apology for the damage that has already been done to the civil rights of individuals with disabilities.

Sincerely,

[REDACTED]

June 24, 2018

Julie Lotharius

julie.lotharius@gmail.com

Dear Sir, Madam,

It has come to my attention that your organization has issued a position statement discrediting rapid prompting method or RPM, a method of facilitated communication for individuals with autism that is based on the use of a letter board.

I am a Neuroscientist with over 15 years of research experience in various neurological motor disorders, most prominently Parkinson's disease, a field in which I conducted extensive research and co-authored more than 15 peer-reviewed, high-impact scientific publications.

It appears that due to the necessity of a communication partner, who prompts the autistic individual to point to specific letters, which then spell out the words and thoughts the autistic person wishes to communicate, you believe that the thoughts RPM is used to communicate are being influenced by the person holding the letter board. One might believe the method to be too subjective and because of the lack of research and absence of controlled scientific studies behind it, that it is not ‘evidence based’ and therefore not valid.

I have witnessed my niece and several of her peers using this communication tool for the last 3 years, and though I also was skeptical in the beginning, and continue to be skeptical when I am not able to see the autistic person actually pointing at the letters themselves and thus being able to 'read' their thoughts, I can say with 100% certainty that in the instances where I have sat next to an autistic person communicating with a letter board and can see them being prompted (simply necessary because these individuals cannot always control their bodies and their motor impairments prohibit them from making successful eye-hand coordination movements), and also witness them constructing complex sentences and expressing complex thoughts and emotions, it is 100% clear to me that this is the best, currently available tool these individuals have to communicate and that you would do these individuals a great disservice to discredit this method and disallow its use in their formal education.

I completely agree that its use is not 'evidence based' from a scientific point of view even though there is a plethora of ‘use and experience' evidence. Rigorous, well-controlled scientific studies with a large population of autistic individuals and unbiased but well-trained communication partners are necessary. Herein lies the biggest challenge, as learning RPM is not an easy task. I have tried to use it with my niece on several occasions but can only get short answers to basic questions because as she has expressed I need a lot more training. For her, it is very taxing to do RPM because of the amount of mental concentration that is required and the significant effort needed from a brain that does not function like yours or mine. She, like many other kids, tends to feel anxious, and it takes many hours of doing RPM with an autistic individual for them to feel comfortable communicating with you. It takes a lot of experience for the communication partner or 'prompter' to know when (and when not to) prompt the individual. Sometimes the person needs help, sometimes they do not. Their body posture needs to be considered, the letter board needs to be held at a specific angle and height, there must be no loud noises or distractions in the room, the communicator must feel relaxed, and the visual system and finger coordination must be working at full capacity, which is a real challenge for these individuals. I have absolutely no doubt that autism is a motor disorder and not a cognitive one.

I strongly encourage ASHA, that instead of discrediting this method, they invest some money to do some proper studies to help validate its use to a broader scientific and academic audience.

Right now this tool is all these individuals have. It has transformed my niece's life, who for many years felt she lived in a silent prison, and also positively altered the lives of all her peers who use it. They can now express intricate thoughts and emotions. They can tell their parents when their basic needs are, how they feel, what their aspirations are, and develop friendships they previously could not. Before she began to 'speak' with the letter board we all thought she was mentally handicapped. Instead we have discovered a bright, loving, kind and hopeful girl who wants everything any 14-year old wants: an education, meaningful relationships, and understanding and acceptance by society.

I hope you will reconsider your position and open your hearts and minds to the possibility that this tool could indeed be a breakthrough if only given the chance.

Sincerely,

Julie Lotharius, PhD
[REDACTED]

June 24, 2018

Jennifer Abramson

abramson.jen@gmail.com

Huntingdon Valley
Pennsylvania

June 24, 2018

Board of Directors
American Speech –Language-Hearing Association (ASHA)
2200 Research Boulevard
Rockville, MD 20850-3289

Re: May 24, 2018 DRAFT Position Statement on Facilitated Communication (FC)

Dear Members of the Board:

I am a parent of a nonspeaking teenager who uses FC as her primary form of expression. Prior to being introduced to FC, we had attempted 'traditional' speech therapy, sign language, picture exchange communication system (PECS), eye gaze devices, and other interventions suggested by multiple speech and language pathologists (SLPs) over the years with limited success. Since using FC, my daughter has experienced multiple benefits including significant academic achievements, new and deeper relationships with family and friends, emerging leadership and empowerment qualities, and a new found sense of self. All this has been transformational and is being realized due to FC.

I am deeply concerned about ASHA's May 24, 2018 DRAFT position statement on FC which is scientifically flawed in its failures to cite sources for its pronouncements, acknowledge or discuss studies or research that support the effectiveness of the method, or incorporate input from FC users and ASHA members with experience as to its benefits; and reckless in its suggestion that the use of FC *leads to* false allegations of sexual abuse and other harms. Before the academic achievements documented over several years in my daughter's school reports are discredited; before the school district finds her 1:1 FC trained para to no longer be necessary for a free and appropriate public education; before the only SLP who has offered her an effective communication method is deterred in providing further FC support for fear of professional liability; and before my daughter's (educational, professional and personal) future potential is unnecessary limited – I urge ASHA to withdrawal the proposed statement immediately.

Nonspeaking augmentative and alternative communication consumers and their families should be allowed to make informed decisions based on unbiased objective research and personal preferences and values. As FC is not inherently dangerous and is in fact benefitting many nonspeaking individuals, ASHA ought to allow the market to ferret out its validity and not summarily end choice through the use of tactics that distort its harms and threaten professional liability of ASHA members under the guise of protection.

Sincerely,

Jennifer M. Abramson

June 24, 2018

Frederic Le Pape

fredericlepape@hotmail.com

To ASHA,

I am the father of a 17-year old autistic boy. We live in the best school district in Pennsylvania. We moved here to Lower Merion because their special education services are outstanding. They recruit the best special education staff (special education teachers, speech therapists, behavior specialists, etc) and have a very low student to teacher ratio. We have been living in the Lower Merion PA school district since Alex was 4 and he has been exposed to the best research-based therapies and tools: ABA, Verbal Behavior, PECS, etc, etc. But progress have been very, very limited. Periodically his IQ has been tested and he was in the Mentally Retarded category. For over 12 years we also had an at-home VB based program for Alex (12 hours per week) overseen by a Certified BCBA.

Alex doesn't talk and we can't know what he thinks. When he is in pain he can't tell us what hurts or where it hurts so it is very difficult to help him. We don't know what he likes to eat or do nor do we know what he thinks.

Well that was before we discovered a method similar to RPM. That was over a year ago in May 2017. Since then Alex's life wasn't changed it was saved. We now can communicate with him. Yes, us, Alex's parents, we got trained on the method and we can have a conversation with him. We discovered our son, after 16 years. We now know what he thinks about the subjects we discuss, what he likes to do, eat, etc. Alex was in prison until then but he is now free.

If you have any doubt about it you are more than welcome to see him in action. Many speech therapists, development pediatricians and special education professionals have done so. They came to observe a session with Alex and all were very skeptical, just like we were when we first started. But like we did they were amazed by what they saw and became advocates for the method. We also had parents of 6 autistic children came to observe and all of them were convinced that the method worked. All of them have started or are in the process of starting the method with their children.

If there was a trick, if this was fake, just like us they would not have been convinced.

Now the most appropriate is to let Alex tell you himself. This is the transcript of a 40 minute session about Autism Awareness month. Alex was asked to write a blog on that theme and this is what he independently spelled with his finger, letter by letter on April 2 2018.

"Imagine sitting on the sideline and never having a chance to join the game. Up until about a year ago that was my story. My name is Alex and I am a non-speaking Autistic. For most of my life people focused only on what I could not do and in reality never truly tested the limits of what

I was capable of. That is until I found letter board. To say my life was changed would be an understatement. My life was saved. A year ago I was introduced to spelling to communicate. This method taught me to build a bridge between my brain and body by pointing to letters to spell out my thoughts. I thought I would never have the chance to share myself with the world, yet here we are. So I want to take this opportunity to challenge the way you view autistics. If you have followed Brian's blog then you have seen what we non-speakers are capable of but now I want you to put us in the game. This year I want to take it even further than awareness. My mission is to educate, encourage and challenge all of you to think of all of the active roles autism can play in your community.

Let's change the game.
Sincerely"

Alex Le Pape

Needless to say that we have figured out that Alex is not mentally retarded at all, quite the contrary. He just needed a method to communicate. This is what we found last year.

As you will understand I am asking you to please withdraw the proposed statements: they are false. Also please issue a formal apology for damaging the civil rights of individuals with disabilities by the Ad Hoc Committee.

Best regards,

Frederic Le Pape

June 24, 2018

Dena McAllister

Response to ASHA's statement against RPM

My son has requested that I write a response to ASHA regarding their statement that recommends withdrawing support from those who communicate using RPM or similar methods. I'm writing not only as a mother to a son who successfully uses RPM, but also as a Research Scholar at a prestigious university, where we study effective programs in education, including those for students with autism. I have experience as a former teacher with a graduate degree in my field. I am trained in several of the evidence based methods for autism, and am well-informed regarding this topic. Since ASHA's statement indicates that they do not believe that people who communicate using this method are actually communicating their own thoughts, they have just stripped my son from any way to respond himself. He could write an eloquent response, but ASHA has already stated that they won’t believe it is his words. So he has asked me to write instead.

I believe that ASHA thinks they are acting with integrity, based on a desire to consider the welfare of those with disabilities who have trouble communicating. So I begin by appealing to this sense of integrity, this desire to protect people like my son who cannot reliably speak with their mouths, and I ask you to consider what damage you may be doing if you are wrong. Those of us who use RPM with our children, were more skeptical of it in the beginning than any of you professionals could ever be. While we would gladly find an answer that works for our children, we parents have become a hardened group who have watched our time and money wasted on multiple therapies that have not brought results. These include therapies that ASHA recommends as evidence-based. But over time, our children convinced us. We watched them tell therapists things that the therapists had no way of knowing. One of the earliest experiences of this with my son was when he was doing a lesson on the fight-or-flight response. He started spelling out L-I-L-Y which was confusing to his therapist who couldn’t figure out how a flower went along with this topic. But as my son continued to spell she realized he was talking about his cat named Lily who runs in fright at the slightest noise. It was an appropriate example to the lesson topic.

While a method like RPM may look simple, it’s amazingly complicated. How well Informed are those people contributing to the ASHA statement? Because anyone who has devoted years to learning this method, understands it’s nuances and believes that it works. My son and I have had our ups and downs in learning this method, partly because we had nobody around us who believed in it or practiced it for so long. But in spite of this, we kept moving forward because this method worked when nothing else did. It allowed my son to learn grade level material through interesting lessons where he could respond to questions and prove his knowledge on tests. It allowed him to explain many things that we would never have known if he hadn’t been able to spell it out - from pain in his jaw (needed oral surgery), to wanting to go to his senior prom (and who he wanted to ask as his date). These basic human needs and experiences would be lost to us without such a communication method. Does ASHA really want to deny these experiences?

While lack of support from ASHA is a real problem for people with communication issues who need all the support they can get, the fact is that these individuals will not be stopped by such a statement. There are too many people who have found their “voice”, and they will not give it up again. My son, who is not prone to name-calling, states that the committee members at ASHA who made such a decision are “ignorant”. We have faced this before - we must constantly educate those around us about this type of communication method. And as those individuals who type to communicate are improving their skills, gaining confidence, and communicating even as certain prompts are faded - society is taking notice. Multiple universities and colleges are accepting and supporting the achievements of these students. Books are being published, speeches are being given, and research is being done with input from all people with autism, including those who type. And just like an interpreter is essential for the deaf to be understood, a communication partner will become the norm for those who cannot speak and need help to be understood.

Anyone who understands autism knows how much help autistic individuals need to regulate their body. It is out-of-date thinking to believe that these individuals are not intellectually intact. But thanks to the mind-body disconnect, often referred to as apraxia, these individuals have difficulty coordinating their muscles to speak, as well as to act in a way that proves their intelligence. This is true of typing too, especially when easily distracted by stims that interfere with movement. A communication partner is trained to help with these issues, so that the person with autism can then type their own thoughts. By placing rigid rules on how the communication partner can assist (such as telling them not to hold the letter board or keyboard), ASHA is preventing them from responding to the current level of support needed by their student. And as my son says, they are also “ruining the nurturing vibes” that an autistic individual feels from a trusted communication partner. Nobody doing RPM is holding the individual’s hand or arm as they type - if that ever happens it is a teaching moment, not a communication moment. Real communication is coming directly from these individuals with autism, and any organization of speech therapists who will not accept all types of communication, needs to rethink its position immediately.

Sincerely,

Dena McAllister

June 25, 2018

Mary Jane Blackman

blackman@eis.net.au

Position comments
The related approaches, "FC" and "RPM" are useful, dynamic activities which should be encouraged. They improve other communication and help develop social interaction and, in some cases can help with movement and sensory issues through better understanding by all involved.

Family, education and therapy feedback shows that, yes there are problems, and each communication partner needs to exercise common sense in each interaction and events arising from this. This is no different from the duty of care when working or living with anyone with severe communication difficulties.

Professionals may choose not to offer these approaches as a matter of personal preference, and indeed should advise families to investigate them carefully. However, your Position Comments do not look at the real-life experiences of those who have benefited from this kind of language use.

Please see "Additional Feedback" below.

Comments re definition

The definition as given is that of an observer, not someone who has explored this option through personal experience over a cross section of clients over a reasonable period of time

It neither takes into account Dr. Crossley's published definition, which you will have read, nor does it look at the ongoing development of strategies arising depending on the experience of the "typer" and the partner or the environment in which the activity takes place. It assumes a static, formal situation, not real-life language use.

Please see "Additional Feedback" below.

Systemic review comments

Although science-based investigations have their place, there cannot be total reliance on them to explore the many variations in human language use (and therefore communication)

Currently the skills being investigated are also those with which people with a diagnosis of autism have many problems - in fact these kind of difficulties in spontaneous interaction are among the diagnostic markers for the autism spectrum.

Yes, it would be very satisfying if using "FC" etc., were also to eradicate these difficulties, but this is not the only purpose of interactive language use. There are far more important issues here.

In relation to line 79, point (d), our experience is that, over a long period of time, this kind of interaction also improves how the person accesses and uses other communication strategies. They are not supplanting other forms of communication.

And further regarding (f) (same page), these issues are endemic in disability care, and I believe that supportive and approachable professional associations are necessary to help various professionals work through these problems

Additional feedback.

Description of our experience with Facilitated Communication and later unsupported keyboard use, 1987-2018

I hope that the ASHA committee will reconsider their arbitrary condemnation of both Facilitated Communication and Rapid Prompt Movement, which enrich the lives of many non-speaking people, including my daughter.

Of course, there are problems, but that is part of being human. It is the responsibility of us all to explore and expand the life experiences of those who rely on us to help them to remain in contact with our world.

My daughter, Lucy Blackman, has accessed language through keyboarding for over 30 years since 1987 when she was in her mid-teens. She is now 45 years old.

Lucy has moved from physical support, to typing on a computer on a desk, etc. with no physical contact from a partner. Over these three decades she completed High School, achieved a post graduate degree and has authored two books, as well as contributing to several others. She has typed freehand in conference presentations and is a real presence in meetings which involve her, such as medical and therapy appointments.

Collaborating through typing, she has developed personalised approaches which build on conventional autism treatments such as behaviour management, activity schedules, task analysis, sensory approaches and enduring modification of behaviours which interfered with her life.

Lucy remains functionally non-speaking, and still has severe difficulties associated with ASD. These interfere with spontaneous and naturalistic use of systems such as PECS and stylised picture systems.

She still has major social and practical difficulties in everyday life, but these are far more manageable than they would have been if she had not had ready access to coherent and fluent expressive language for three decades and been able to use it flexibly with some of the people involved in other aspects of her life.

Our experience is that Facilitated Communication and similar keyboard access are not a “treatment” for autism, but a “strategy”. Used with care, it is useful and empowering for all parties. It can augment other strategies and give insight into why other approaches do (or do not) succeed.

Introducing this approach usually involves a speech pathologist or a teacher working with language-based activities. Ideally one transfers it as soon as possible into a real-life situation where the communication partner can create a rewarding experience.
When working with someone who did not achieve interactive language in early childhood, small steps in terms of lifestyle adaptations need to be carefully weighed and offered in the most rewarding way. This is especially so if there is an underlying language processing disorder, as in Lucy’s case.

Our experience and that of the dozens of typing “partnerships” I have met is that standardised testing is not appropriate to this strategy. The role of the facilitator may not be a neutral position, but it does not mean that it involves influence, rather of offering an opportunity for expression.

Some people may learn to perform certain communicative tasks, others will not. It is very important to remember that there is no “pass or fail” in this activity. And even more importantly, it can be accommodated in other therapeutic and training approaches, often will improve outcomes in these as well, and is worth the effort.

With many thanks,

Mary Jane Blackman

June 25, 2018

Drs Sjoukje W. Zijlstra

sjoukje.zijlstra@marble-psychology.com

My concern and disappointment when taking away the letter-board (Rapid Prompting Method) for non-speaking autistic persons

Describing self

I am a clinical child psychologist

Other interventions, behavioural techniques, or communication methods

Visualization cards (picture cards) - sign language – written communication

Describe how access to a letter-board has improved the individual's life

Since the young client is able to 'talk' with the letter-board, he is able to communicate significantly better and express' what he really want to say or think. Before, I tried to guess his feelings and sayings by reading his body gesture, facial expressions and limited produced sounds. However it confused and stressed the young person, because not ALL the interpretations were correct. The interpretations stayed limited. Visualization / picture card cannot describe a full situation and it does not lead to a conversation. Due to motor apraxia as well, the young person is currently not able to write or type, however the young person is able to read. The person can read however without letter-board the person cannot answer or express himself.

How preventing the individual from accessing his preferred communication method will affect him.

If the person is not able to communicate with the letter-board, he will not be able to speak anymore and nobody will know what he has to tell and what he knows. He is not able to continue his education and there will be stagnation in his intellectual growth.

June 25, 2018

Nico and Jodie K Agnew-Navarro

Dear ASHA:

I am very concerned about your position statement in regards to Facilitated Communication and Rapid Prompting Method. Communication is a human right and ALL people should be exposed to a variety of communication options with the ultimate goal that they are communicating their own thoughts and feelings rather than what others are assuming they want to talk about. Invalidating anyone's communication system is unjust and unacceptable. Following is my son's story:

Facilitated Communication not only gave my son his voice, it gave him his life . . .
Nico is nonverbal and was thought to not only have autism but an intellectual disability. We had tried everything imaginable for our son to communicate with us, signing, PECS, and a variety of voice output devices, all with limited success. Then one day, I get a call from my son's special education teacher on my cellphone telling me to drop whatever I was doing and come to school immediately. I cancel everything remaining on my schedule that day and race to school not knowing exactly what I was going to find. When I get there, Nico is with his special education teacher and speech pathologist. Using an approach called "facilitated communication," he is answering yes/no questions and I am shown a video of him typing out a sentence! Nico is communicating for the first time in his entire life! He is ten years old.

Nico was finally able to communicate his own thoughts and feelings! But, that was only the beginning. We quickly learn that he could spell very well and that he had learned everything taught in his classes! He went from modified class work, to doing the same coursework as his peers! Nico went from an IEP goal of "counting 10 objects" to doing grade level 5th grade work all because he could now communicate what he knew. Nico just completed 11th grade, is fully included in his High School and just completed Algebra II. This would not be possible if he was not able to communicate by typing.

Nico's miraculous break through is all because of facilitated communication. I shudder to think of where Nico would be if not for facilitated communication. He would not be able to communicate his own thoughts and feelings and would still be considered as having an intellectual disability. Facilitated communication gave our son his voice and his life.

Sincerely,

Jodie Agnew-Navarro, MA
Credentialed Special Education Teacher

-My son wanted to share his experience with fc with you as well:

My name is Nico and I am autistic and nonverbal. I use facilitated communication to communicate. Before I typed I felt like I was trapped in my own mind. No one understood me or knew that I was in there. I was sad and wanted to communicate but I didn't know how to and I was frustrated and discouraged so I acted out a lot. I was a lost soul. I felt retarded and I felt like a different person than I am now. I felt like the only person in the world who was smart but couldn't tell anyone. Saying that facilitated communication is not valid is a total lie. I am a awesome all-star and I am communicating my own thoughts. You need to believe in us and support us.

Nico Navarro, 17-year-old awesome all-star communicator

June 25, 2018

cathiedavies@optusnet.com.au

I have just submitted my son's feedback to regarding the ASHA Position Statement. He is an FC user. He typed the following, which I re-typed for him into the "Additional Feedback" box on the portal:

> I want to say that FC has changed my life and given me hope for the future.
>
> I was angry and confused before I learned to type.

As requested, I am forwarding this to you as a record of his submission.

Regards,

June 25, 2018

Julie Sando

juliesando@autisticallyinclined.com

I am writing to you today in response to the draft position statements issued by ASHA's Ad Hoc Committee on Facilitated Communication (FC) and Rapid Prompting Method (RPM).

I am an educator who works with autistic students and their families.

I've been in the field for 20 years. I did ABA but I walked away, feeling like I was being trained to be cold and heartless. For example, to stop a child from running into the street, I was told by my BCBA Supervisor to let this sweet 5 year old autistic child run into the street, then bring him inside, place him facing a corner, tightly hold his arms by his side, place my knee in his back as I sat in a chair, apply pressure so his face fits into the corner and he can't move, firmly say "no", make him stay like that for 5 minutes, and repeat until he no longer runs into the street. They had me hold him, straight-jacket style, with his face in the corner. This is what "science" suggested.

It's been quite a journey. I went on to study relationship-based approaches. This felt so much better because I could look at the human being in front of me. I was trained to value and understand what we were seeing in a different way.

There was a reason, a valuable reason, the child was stimming. It was seen as a doorway into the child's world where we could connect and expand from.

I was trained to get excited when they spoke and to do anything fun and motivating that I could to inspire more speech! I worked my butt off to get a sound out of a child and when I did, it was like I won the lottery!

And then, one of my families I had known for 14 years changed everything yet again for me.

The boy was 4 when I first met the family. He had done ABA, and we were both in relationship-based modalities together for many years. At the age of 18 he spoke about Wiggles videos all day long. We did our best to use that motivation to elicit more speech. We answered his repetitive questions with a smile on our faces, to show him how much we appreciated his voice. We talked about The Wiggles as much as he needed to as a way to create that doorway to more. We were so proud of him (and ourselves) when he started to show us that he could do basic single-digit multiplication!

And then, at the age of 18, he did RPM. He worked with a trained practitioner and his mom learned how to be his communication partner as well. This is the mom who knew this guy to love The Wiggles and who worked super hard to do basic math with him. This is who he was to us. With every fiber of our being, this is what we believed. It's what we saw, day in and day out, for years.

He started out needing prompting, of course... just like all modalities do (speech therapy and ABA included). This is the stage where they worked on educational material that has one possible answer so they knew how to guide him to the correct letters. There was no open communication when he's being prompted to a letter. First he needed to build up his motor skills. As he gained more confidence and built those motor pathways up in his brain, they were able to work toward open communication, without prompting.

What he had to share shattered the beliefs we had held for years. It would have been easy to want to stay in that comfortable place but there was no denying his voice through this letter board. He expressed that he actually hated The Wiggles. He was stuck. He needed help moving away from The Wiggles. He wanted us to ignore his impulsive voice. He wanted to work on his purposeful voice which he had not yet gotten out. Now, a few years later, he is getting his purposeful speech out as he points to a couple of letters, he is able to say the whole word, and sometimes a phrase or sentence!

Before, he was stuck on his iPad. We were stuck with him, in Wiggles-land. Now, he has asked to take away his iPad, and he has asked for chores. He wanted to learn how to clean a toilet, how to make himself breakfast, how to do the dishes, and so much more. We had no clue he had these desires. From someone steeped in relationship-based approaches, I would have NEVER thought about asking him to clean a toilet! NEVER! To him, this was a welcomed feeling of normalcy. He wants to be like everyone else. He has hopes and dreams and desires like we all do. And he's checking them off a list one by one.... he is now has a girlfriend and he's taking online college level courses. That's right... he is no longer limited by his speaking voice's ability which reflects a much younger level. Through the letter board he is able to show us so much more than we could have ever imagined.

This family is not the only family who I have personally witnessed great changes in through RPM. It is something I highly recommend to families and will continue to do so, because I have personally experienced the depths of change that no other approach could provide these families.

As a professional, I have made the decision to admit when I had it all wrong...many times throughout the years. And I will continue to do so. As a professional and a human being, I am never done learning. The first time I realized I had done this was with ABA. Don't get me wrong, ABA has worked wonders for some. And it can be done in a more respectful way than the way I was trained in. But that doesn't mean it's right for EVERYONE (kids, families, and professionals included). If that were the case, all the other programs wouldn't exist.

When a trusted organization like ASHA makes a blanket statement, deeming professionals as incapable of seeing when something might not be done in the best way, it breaks my trust in ASHA.

When ASHA tries to discredit RPM and the voices that have come from RPM, without personally speaking with the countless individuals whose lives have dramatically changed for the better, it breaks my trust in ASHA.

Ironically, the result of ASHA's actions discredits ASHA's voice.

What makes a great professional is when we can admit when we were wrong. I've experienced this to actually build greater trust and respect in our community.

I hope ASHA listens, as the most important people in the community are speaking about this topic - those who are communicating through their letter boards themselves.

Has ASHA & the Ad Hoc committee sat one on one with these families to listen to each experience? I am disappointed to realize that the group of individuals ASHA selected to develop this position statement includes no one with direct experience in the methodologies in question.

The Ad Hoc Committee is a group of individuals that have made publicly documented, derogatory remarks about disabled individuals who use these methods; and have personally attacked those who have supported them.

This position statement was clearly not drafted by unbiased individuals, and multiple viewpoints were not considered in reaching these extreme conclusions.

ASHA must consider pursuing further research into RPM itself before making their official position on the subject.

Furthermore, ASHA is contradicting their own Communication Bill Of Rights Through this statement.

Suggesting that those who use spelled communication are not independently communicating is a violation of the civil rights of these individuals.

I stand with the countless families, asking for the following:

1) That the proposed statements regarding spelled communication be withdrawn.
2) That ASHA issue a formal apology for the damage that has been done by these statements to the civil rights of individuals with disabilities.

I hope that trust in ASHA can be restored by your upcoming actions.

Sincerely,

Julie Sando
Director, Autistically Inclined

June 25, 2018

Marci Nace-Britt

marcinace@hotmail.com

To Member of the Board of ASHA as well as members of the Ad Hoc Committee,

I am a Speech-Language Pathologist who recently became aware of your position statement on Rapid Prompting Method. I am disappointed by the position ASHA is proposing. RPM is a facilitator based communication method and is highly dependent on prompting the student initially, as are most therapy techniques I use with clients who are non-verbal. The use of the letter boards, the laminate board, and they keyboard needs to be taught through prompts and cues as does the formation of sounds and words. The end goal of RPM is for the student to be able to communicate without the prompts as is the end goal in traditional speech and language therapy.

I am also confused as to how the Ad Hoc Committee members were chosen, as I am aware that there are members of the Board who have actually observed RPM sessions. Why are they not part of this committee since they would seem to have the most knowledge about how RPM works? The members of the committee have not seen this intervention in person, which would seem to be a logical step in reviewing the technique. If the lack of research studies is an issue, then research studies should be conducted by unbiased individuals before the technique is discredited. A lack of research does not indicate a lack of evidence for the success of this technique as empirical evidence is abundant.

As an SLP, I too was skeptical when I heard about RPM. However, seeing it first hand with a client I worked with for years was life changing. This method has allowed him to express so much more than rote phrases or the occasional break-through novel speech. By working with an experienced communication partner using RPM, he now has a voice. He is able to express himself in ways that would not have been possible and are still not possible for him verbally. In the last session I sat in on, he was typing on a keyboard with little to no prompts given. The only prompt was to "keep going" when he began to fidget with his fingers instead of completing the task on the keyboard. I have also had the opportunity to observe many other children, young adults, and adults who have finally been given the chance to access their voice through RPM.

I would respectfully ask that you reconsider your position. Please do not take away an effective means of communication for so many. It is their human right to be allowed to communicate and our ethical responsibility to find the best means possible for them.

Regards,

Marci Nace-Britt, M.S., CCC-SLP
Speech-Language Pathologist

June 25, 2018

Ivonne Mera

ivonnemera@hotmail.com

Re: Proposal to preserve communication choice

I am a mother of a 19 year old non-speaking autistic girl. My daughter was diagnosed with autism at the age of 2.

Since then I have spent 17 years searching for the best therapy, intervention, treatment, method, regimen, practice, and procedure that could or would help my daughter with communication, skills, compulsiveness, impulses, non-purposeful movements and non-purposeful vocalization. This search has also led me to a few different countries for courses, conferences, and symposiums on the subject of autism, cognition and communication.

A number of Speech Pathologists have assessed my daughter and have treated her for countless of hours throughout the years. She had ABA/IBI full time for years with no improvement what-so-ever. She then moved into the public school system with a panel of experts and professionals specializing in Autism, including an autism resource teacher and certified speech pathologists.

Under the recommendation of these experts the school focused on PECS for at least 9 years with absolutely no gains. Her frustrations grew, her sleep became more erratic and she retreated into her own world more and more as time went on.

Then, in 2015 I heard about RPM through a documentary of an autistic child's journey out of his world of silence. "No stone unturned" is what I live by when it comes to my daughter's fight for a quality of life she desperately deserves and so I looked into this method.

I made a calculated decision to try RPM with my daughter. In April of 2015 I brought my daughter to Soma's center in Texas. As her first session with Soma began, I was amazed as I witnessed my daughter engage and answer questions for the first time in her life.
As an analytical person I scrutinized each movement Soma made. I dissected each step, angle, each word said, intonation, volume, and pauses. To inspect a "therapy" this closely is a skill I have had to learn after so much time wasted in therapies and methods that have stolen years, almost decades of my daughter's life. There was nothing suggestive or manipulative about her teaching. She did not take my daughter's hand. My daughter's movements toward the letter board where completely independent. There is no doubt that she understood the questions in the lesson.

Immediately after this first session my daughter's demeanor changed. The smile she lost long ago returned. Her joy was evident that day and in the days to come. Her restlessness at bedtime was replaced with calm satisfaction. Satisfaction at knowing that finally she was being heard, she finally had a chance to move toward communication and that we knew she was "in there". As you could imagine I was elated.

On our return home I met with my daughter's teacher. She viewed all the videos of my daughter's sessions with Soma. She also came to the same conclusion I did and had my daughter's education plan altered to include RPM lessons throughout her day. In the months following my daughter would show progress in every area of study.

Tragically during a routine visit to the school a Certified Speech Language Pathologist from the board intervened at the mention of RPM. She not only discredited RPM but she prevented my daughter's teacher to continue with this method in the classroom. This Speech Pathologist did not even care to watch my daughter answer questions on her letter board. She did not give her a chance at all. Her words parallel your position statement. She said, "there are no studies on RPM, the school board does not recognize this as a method of teaching and you need to stop this immediately".

Sadly because of this, her teacher could not continue. Once again my daughter retreated, her frustrations grew, she no longer slept well and there where many days where she would just sit and cry.

Just this year I was reintroduced to the letter board as a form of communication by another mother of an autistic child. My daughter is now on the right path to communication, but she was robbed of three years where she could have had a chance at an education, three years that she could have communicated her needs, wants and expressed her personality.

If this damaging statement by ASHA finalizes my daughter's future at an education will gravely be affected. Her voice will be disregarded and she will be silenced yet again. No professional body will take her seriously if your statement solidifies. I cannot image if she has a medical emergency that only she can describe in her own words, her words not be taken seriously because you have discredited her way of communicating.

I know of stories of children and adults that have learned the letter board through RPM and have been able to express medical situations that only they can because they, not their mom, not a communication partner, are the only ones who can specify what physical pain they are in and where that pain is. How can you suggest that these words are not that of the disabled person? How can anyone know something that is going on in another person's body?

For ASHA to suggest that this method of teaching and communicating is "not recommended", "information obtained through the use of RPM should not be considered as the voice of the person with a disability" and that the messages delivered using RPM may be facilitator influenced, is deplorable, irresponsible and damaging to every non-speaking person using this method of communication.

As you have pointed out,

> (a) to date, there are no studies of sufficient rigor to demonstrate a link between any changes in the person with a disability and the RPM intervention,
> (b) no studies on RPM have tested authorship or authenticity of messages delivered using RPM, and
> (c) there is no scientific evidence supporting the claims of RPM proponents in relation to education or communication.

These studies are long overdue!

How can a body of professionals whose mandate is, "*Making effective communication, a human right, accessible and achievable for all*", yet attempt to put out a position statement to dismantle and discredit a methodology without looking at the evidence of countless individuals whose quality of life has changed for the better. How many non-speaking individuals using RPM where interviewed by this Ad Hoc Committee? How many committee members have personally sat down with members of the non-speaking community? How can you willfully silence the countless individuals yet to be helped by this type of communication?

Not only should this position statement be retracted but it should be the responsibility of ASHA to conduct and fund unbiased studies on RPM to accredit and validate this method for the future of non-speaking individuals. Communication via a letter board should be backed by ASHA so that the school boards adopt this method to ensure the right to education for all individuals who are non-speaking.

In our system of law a person if presumed innocent until they receive a trial. At trial, evidence that is beyond reasonable doubt is the standard required to validate a criminal conviction. Where is your evidence that the words formed by non-speaking individuals are not their own. You are presuming guilty without a fair trial, without witnesses and without considering the evidence.

Sincerely,

Ivonne Mera

June 25, 2018

Maria McGugan RMT
Matthew McGugan

mariamcgugan.rmt@gmail.com

I am writing with regards to the present attempt of the ad hoc committee of the American Speech-Language-Hearing Association (ASHA) to deny communication choice and access for children with disabilities.

Our son Matthew just 18 years old in April and he was diagnosed with moderately severe autism, severe global developmental delay and ADHD. Like other children in the spectrum Matthew deteriorated in his speech at the age of 33 months which prompted us to seek diagnosis. From then on we started ABA, speech therapy, occupational therapy and physical therapy for gross motor needs. At the age of six years he was accepted in the intensive behavioural intervention in Ontario using ABA principles and was discharged at age nine because of his severity in autism and lack of major improvement. Matthew did learn the basics of sitting down and attending to task which helped him in going to school full time. After kindergarten, Matthew had attended a special class geared to developmental delayed children and always had been allocated a one-on-one educational assistance.

Matthew all through his autism diagnosis was introduced, taught, treated using speech communication such as PECS, verbal behaviour, sign language, PICS but none of these had really helped him in communicating and thus inappropriate behaviour were always attached to the lack of means to communicate. Matthew also had a severe sensory dysfunction and has stimulatory behaviour such as hand flapping and busy hands and hence the prologue2go was not considered an option. His stimulatory behaviour always had impeded Matthew in using PECS and other devices such as keyboard and ipad.

In fall of 2016 my friend Kelli Pallett had asked me to go to a workshop about the communication system that her son has started successfully using. I was very skeptical because as I had explained above Matthew had tried so many communication systems with no success. However, I went to the workshop and that was when I was introduced to the use of the letter board not just for communicating but a possibility of using this for academic at school. I have met parents who all of their children do not speak like Matthew. All of a sudden I felt like I belong to an autism group who really understand what we go through with Matthew. Matthew had a couple of letter board sessions after that and the very first sentence we heard from him ever was “I ALWAYS IMAGINED DRIVING A CAR” and we were in tears hearing from our son who was 16 years old. In March 2017 Matthew had more regular letter board sessions between Ms. Kelli and myself and Matthew started to communicate to us about his frustrations at school and at home. In December 2017 we introduced the use of the letter board to his high school with a thirty-minute lesson to his teacher and two educational assistants. They were all very impressed and surprised with his skills in spelling, answering questions and doing math calculations. None of these he was taught for the time that he was at school since his day at school were only sensory activities, matching, and singing nursery rhymes even at the age of 17.

Matthew had spelled that he is frustrated with people not believing in him and he has had it with the use of timer all the time. Matthew had spelled notes for me and dad for Mother’s and Father’s Day for the first time and thank you letters to his teachers. When he wasn’t feeling well he would tell us in detail what is bothering him and that helped us tremendously when we talked to the doctors.

In February 2017 the school approved the use of the letter board for Matthew in the goal that this can be a part of his communication system. I personally went to the school and trained the teacher and an educational assistant on how to use the letter board in a consistent manner. The SLP tried to modify it having the letter board placed in an easel but the inappropriate behaviour started again and escalated. After two weeks of the modification, we stopped the use of the letter board with modification and after the school approved to follow how Matthew has learnt to use the letter board the behaviour ceased immediately.

Matthew started his self-injurious behaviour at the age of eleven and he was helped by different agencies again with no success. The only thing that came about was a few assessments confirming that Matthew is at 18 month old level in communication. When Matthew started his letter board sessions consistently in March 2017 his inappropriate behaviour such as outburst, self-injurious behaviour stopped.

Presently, Matthew belong to a group who he has made friends since 2017 and they called their group NO NONSENSE DUDES, which by the way Matthew came up with the name and the group voted for it. Matthew had never had friends nor he was ever invited to anything. Now he has six other boys he is friends with and when they meet up they share their thoughts and play board games to name a few.

I do not understand the intent of what your association is trying to prove. I am also a therapist and I follow research based type of treatments for my patients. However, the low tech letter board form of augmented communication has proven that it really worked for people like Matthew. He can tell us immediately what he has in mind, his needs, what he wants to study, what he wants to do in the future, etc. Matthew from the very beginning had expressed his interest in language arts and he wants to write his book, his story and also learn history, geography and literature.

I am hoping that after you have read so many letters from our children and adults with autism, parents, and other professionals that you would really reflect and think about the outcome of this on how it will affect the lives of people with special needs who could not talk.

Please have an open mind and as what will Matthew say, DO NOT BE NARROW MINDED and rigid. The Speech Association can really help our children to shine and feel good about themselves that they are useful to their family and to the community.

Matthew's note to his teachers this year: TO EVERONE WHO SUPPORTS ME. THANK YOU FOR BEING AMAZING THIS YEAR. I AM APPRECIATIVE OF YOUR BELIEF IN ME. MATTHEW THE INCREDIBLY STUDLY GUY.

I thank you for your time and consideration.

Regards,

Maria McGugan, Parent B. Eng., Registered Massage Therapist Canadian College of Osteopathy (Thesis Writer)

DEAR ASHA BOARD,

I AM AN 18 YEAR OLD GUY WITH AUTISM. ONLY SINCE I LEARNED TO USE A LETTER BOARD HAVE I SEEN A FUTURE FOR MYSLEF THAT DIRECTLY TOTALLY IS A FUNCTION OF MY ABILITY TO EXPREESS MORE THAN MY BASIC NEEDS. TO SAY MY LIFE HAS CHANGED IS AN UNDERSTATEMENT! HAVING THE ABILITY TO SHARE MY THOUGHTS AND MY FEARS IS WHAT IS SAVING ME FROM A LIFE OF NO MEANING OR PURPOSE.

SINCERELY,

MATTHEW

(Matthew McGugan, June 25, 2018)

June 25, 2018

Nina Hancharik

ninahancharik@hotmail.com

Dear Members of the ASHA Board of Directors,

I am the mother of an autistic child and I am writing in response to ASHA's Position Statement (Draft) on Rapid Prompting Method dated May 24, 2018. It is apparent that ASHA's stance is not based on a true understanding of the method. I urge ASHA to observe RPM sessions, read the books written by Soma Mukhopadhyay and interview RPM families as well as individuals who have used the method to achieve independent communication. There are many!

My son participated in "evidence-based" practices such as traditional speech therapy and Applied Behavior Analysis for years to no avail. In fact, I would argue that he was harmed by such practices in that they resulted in undue frustration, reduced self-esteem and lost opportunity to access other interventions (such as RPM) that would help him. My son found his voice 3 years ago as a result of Rapid Prompting Method. At almost ten years old, he has very limited and unreliable speech. However, he has learned to communicate by pointing to letters and his quality of life has improved immeasurably. Before he could communicate, he was locked in a world of silence, which manifested in outbursts of frustration and anger.

RPM has been life-changing for my son and for our entire family. Because of RPM’s emphasis on purposeful movement, many areas of his development have improved in addition to communication. He can now dress himself, use utensils to eat, operate kitchen appliances, play games and participate in sports. In addition to my own son, I have personally witnessed many individuals successfully and independently communicating by pointing to letters on a letter board or keyboard. To disregard the method these individuals used to reach independent typing would be irresponsible and contrary to the very mission of ASHA.

ASHA uses the lack of scientific evidence supporting RPM to conclude that RPM is “pseudoscience”. However, an untested treatment may be equally effective (or more so) as treatments that are supported by evidence based research. The untested treatment is simply “not empirically supported yet.” A rigid adherence to the idea that we need to only provide evidence-based interventions may deprive users of optimal treatment.

I ask you to please withdraw your position on Rapid Prompting Method for the sake of my son and the many other individuals who can benefit from it.

Sincerely,

June 25, 2018

E. John McConnell

judgemcconnell@msn.com

Board of Directors
American Speech-Language-Hearing Association (ASHA)

Dear Board Members:

I write in opposition to a policy apparently under your consideration that would, if followed, limit communication options available to nonverbal individuals.

The conclusory assertion that augmented communication sometimes call facilitated communication has been scientifically discredited is nonsense - unless you are using "scientific" in some adulterated sense. I am the father of a 34 year-old autistic man who lost his speech at about the age of six, has benefited enormously from this method, obtained a GED and passed several college courses. Further, as a sitting trial judge for nearly 20 years, I am well aware that academics who hold themselves out as "experts" in the communication field are often wrong or at least contradicted by other "experts." Given the lack of knowledge of the etiology of autism, we should be expanding not limiting treatment modalities. Your apparent policy would discourage innovation by creative therapists, and diminish the quality of life of many nonverbal people.

I can only conclude that the motivation underlying the proposal is economic, and that it is advocated by therapists wedded to old methods who wish to limit competition from those who are more innovative and creative.

E. John McConnell
Wailuku, Hawaii 96793
judgemcconnell@msn.com

June 25, 2018

Laura Green

laurakleingreen@gmail.com

ASHA
Attn: Board of Directors
2200 Research Boulevard
Rockville, MD 20850-3289

Dear ASHA Board Members,

I am writing to express my concerns for your troubling draft position on RPM. My daughter is 16 years old and nonspeaking. She has a rare genetic disorder and has been spelling to communicate for the past three years. Prior to that, she worked with skilled speech therapists, occupational therapists and a physical therapist. She had a home-based floortime program along with weekly swimming, horseback riding, OT, speech and physical therapy appointments.

From the age of two, we immersed ourselves in sensory integration therapy, PECS, Proloquo, sign language, vision therapy and oral motor therapy. We had very slow progress in all these areas, but most of our therapists were loving, patient and playful. Our daughter was always much more interested in the other kids in the waiting room than in her adult therapists and the repetitive games and exercises, but the theory was that she needed to communicate at higher levels of reciprocal communication with adults before she would be ready to engage with her peers. So by the time she was 13, we had come to accept that pressing the buttons that said I WANT ICE CREAM on her iPad or tossing a copy of the book GIVE THE MOUSE A COOKIE across the room was the extent of her communicative abilities.

So when one of her floortime players picked up a young adult novel of my older daughter’s and started reading to my younger daughter, I was surprised to see my nonspeaking daughter listen intently for 20 minutes. The floortime specialist suggested that we meet one of the RPM providers in our community. After much prodding, we agreed to give it a go. I watched and even though I was skeptical, I saw that it was doing no harm, and for the first time, my daughter was sitting upright in a chair, working very hard and loving it.

It wasn't until I spent a weekend watching other kids work with skilled providers, their teachers and parents that I started to think that there was something to this. The material was age-appropriate and engaging. The kids had bodies that were often hard to control but they were truly spelling, typing and communicating. As a parent, it was very hard to reconcile. My daughter's longtime speech therapist had tears in her eyes as well. We had spent many years not assuming competence and many years thinking we knew my daughter as well as many other nonspeaking and unreliably speaking kids. We didn't know them, we engaged them in games with stuffed animals and tried to get them to do the same puzzles meant for 2 year olds week after week. And yet, while we had grossly underestimated my daughter, we had at the same time known her all along. Everything she has spelled (and with a variety of skilled communication partners) has been exactly true to the person we always knew was locked inside.

Today, my daughter has many friends and classmates, along with smart, funny and caring adults in her life who believe in her and partner with her in experiencing the world in an intellectually stimulating environment full of shared joy and passions. It reminds me of something our floortime-based psychologist said to us when our daughter was young. She said, "At the end of the day, what do we all want for all our children? We want to be able to sit around the dinner table, laugh, connect and enjoy one another." We are so grateful that we live in a community chockful of spellers, communication partners and educators who believe in our kids.

We hope that you will withdraw your proposed statements about RPM. As a high school teacher and as a parent, I can certainly understand that learning about RPM and accepting it is a process that takes time and an open mind. I assure you that if you take the time to meet the kids and adults who spell or type to communicate and some of the truly talented providers who work with them, you will have no doubt understanding the authenticity of this method and the freedom and dignity it grants to some of the most at-risk people in our society. My older daughter interviewed my younger daughter for a presentation she gave to her fellow high school students about having a younger sister with disabilities. When asked for her permission and advice, my younger daughter spelled: WE CAME TO MAKE A CHANGE—A CHANGE IN HELPING KIDS FORMULATE NEW WAYS OF SEEING HORRIBLE STEREOTYPES. START BELIEVING STUDENTS OF ALL KINDS CAN LEARN. In closing, we hope that you will support the members of your organization in formulating new ways of seeing horrible stereotypes and start believing that all students can learn.

Sincerely,

Laura Green

CC: ASHA Board of Ethics, Heather Bupp, Esq
ASHA Governance, Mary Moore

June 23, 2018

Anonymous Provider

From: Provider

To: American Speech-Language-Hearing Association (ASHA)

Re: Proposed Position Statements on use of Facilitated Communication (FC) and Rapid Prompting Method (RPM)

To Whom It May Concern:

I am a practitioner working with a variety of neuro-diverse clients ranging in age from 4 to 40 years old. For years I worked with clients supporting their sensory and motor needs by incorporating sensory diets, vestibular input, therapeutic listening, floortime and many other techniques. Too often I found myself implementing therapeutic approaches with clients who were unable to express if they enjoyed, preferred or disliked the approaches I was using.

As I began using stencil boards and supporting the visual and motor systems to spell I saw a whole different side of ALL of my clients. Students who used to constantly seek movement were now sitting and attending for 45 minutes straight. Others would hand me the pencil or stencil boards ready to work and some even spoke to me saying “I need the laminate board to answer.” Students who had meltdowns daily suddenly stopped. Clients who rarely initiated or participated consistently through any previous therapeutic approach were still and silent for most of our sessions. Students who had never reliably answered their parents’ daily question, “How was school today?” were able to respond, “I learned about Georgia O’Keeffe.”

If I could have known what was unfolding in front of me, I would have loved to have had a research study in place, ready to document and measure each student. Although unmeasured, I saw measurable changes in my students’ posture, mood, confidence, speech output, eye contact, initiation and most importantly relationships with everyone. To remove this right to freedom of speech and access to communication would be detrimental to the over 100 neurodiverse children, teens and adults I know, not to mention their entire families and friends. These individuals would go from being a part of a community to being observers and passive participants in their lives.

I respectfully request that you withdraw the proposed position statements. Thank you for your consideration.

June 21, 2018

Lyn Jordan-Coker

lynjordancoker@yahoo.com

Dear ASHA Board of Ethics et al,

As a grandmother of three (3) grandchildren with Autism, I am appalled at the idea that your ad hoc committee feels they can deny my grandchildren the right to learn to communicate in other methods they deem ineffective. I most strongly disagree with the ad hoc committee's judgmental view that "their methods" are the "only" methods acceptable. To a person that cannot speak, the ability to communicate is priceless, whatever the methodology. As verbal adults, what right do we have to deny the non-speaking access, in any form, to learn the basic right to communicate?

My eldest grandchild, who is non-speaking, lights up when asked his opinion because, now, with access to a letterboard, he can communicate his feelings and thoughts. School has now become a place for him to add his "voice" with great success and accomplishment. Your organization should never want to negate these accomplishments.

I am asking ASHA for the following: 1) that the proposed statements regarding spelled communication be withdrawn; and 2) that ASHA issues a formal apology for the damage that has been done by these statements to the civil rights of individuals with disabilities.
I feel a letter of response by you to me is appropriate and necessary. I look forward to hearing from you shortly.

Sincerely,

Lyn Jordan-Coker

June 25, 2018

David Hancharik

david.hancharik@viasat.com

Dear Members of the Board of ASHA,

I am the father of a 10 year old autistic child and I am writing in response to ASHA’s Position Statement (Draft) on Rapid Prompting Method dated May 24, 2018. It was obvious to me that ASHA’s stance is not based on a true understanding of the method. I would urge ASHA personnel to witness actual RPM sessions, and attend one or more of several RPM workshops where autistic persons respond to questions real time. There are many of these and it is easily seen that there is no manipulation or pseudoscience involved.

I have many examples of my son responding to questions accurately where the “prompter”, be it myself, a family member or a professional provider would have no knowledge of the correct answer. A perfect example is a game that my son loves to play: Solitaire Chess. He does not have the motor skills to move the pieces himself, so he uses an RPM board to the name of the piece, rank and file to make his moves. When I started playing with my son, I would first study the board to determine the sequence of moves (there is only one combination) so that I would know immediately if he was making a mistake. This would take me several minutes. After noting his proficiency relative to my own (he was much faster), I stopped studying it to make sure that I was blind as his facilitator. My son was equally proficient without my having knowledge of the sequence of moves.

We tried many so-called "evidence-based" therapies, including speech therapy and ABA with negative results. His behavior was dominated by frustration. Within just a few months of RPM, his behavior improved drastically. My son's quality of life is so improved that his entire demeanor has changed for the better. His motor skills have even improved, presumably because purposeful movement allows him to communicate, which gives him the motivation to work harder to control his body. My wife and I fear far less about his future.

I am an engineer, so scientific method is engrained in my thought process. I have seen the methods of data collection used to support ABA, speech therapy and special needs education. Quite frankly, these methods would not pass muster with anyone that follows scientific method. These methods are largely contrived. True gains in quality of life for an autistic person are not measurable using these techniques. My empirical data is that exactly 100% of the families I personally know with autistic persons attest to the vast improvements realized with RPM, as compared to other therapeutic methods.

I ask you to please withdraw your position on Rapid Prompting Method for the sake of my son and the many other individuals who can benefit from it.

Sincerely,

June 25, 2018

June 23, 2018

Sally Smith

sallytuismith@gmail.com

Dear Board of Directors of the American Speech-Language-Hearing Association,

We are writing to you to express our concerns about the draft position statement issued by ASHA's Ad Hoc Committees on Facilitated Communication (FC) and Rapid Prompting Method (RPM).

We are the parents of a 7-year old son with autism who has very limited spoken language. Despite many years of speech language therapy (from age 2) and many other interventions, our son's ability to communicate through spoken language has not increased significantly.

Two years ago our son started using the letterboard. Through the letterboard he has, for the first time, been able to demonstrate and clearly communicate his ability to understand and engage with age-appropriate content that is otherwise not visible. This has encouraged us and his school teachers to expose our son to a much wider range of activities and topics and treat him like a person of normal intelligence. As a direct result of that, our son is much more engaged with his environment and participates much more fully in our family, at his school and in our community.

Your draft position statement, which recommends against the use of RPM and FC, is largely based on the argument that there is a lack of scientific evidence supporting these methods. As a reputable organisation ASHA should not discredit these communication methods without having scientific evidence to support such a position. Therefore we suggest that you take a neutral position until robust scientific evidence on these methods becomes available.

As parents, we have witnessed the effectiveness of communicating with letterboards for non-speaking individuals first-hand with our own child, and with other children in our community.

Your draft position statement will, and has already had, a negative impact on those individuals using letterboards to communicate, and others who could potentially benefit from these methods. We are deeply concerned and disappointed that ASHA has published this draft position statement which does not appear to have had any input from individuals and professionals that have first-hand experience with these methods.

Please withdraw the proposed position statement on RPM and FC and formally apologise for the negative impact that has been done by the draft statement to the human rights of people with disabilities.

Thank you for your consideration. We look forward to receiving your response.

Brian McKenna

brianmmck@gmail.com

ASHA Board of Directors,

My name is Brian McKenna, and I am the father of a mostly non-verbal child with PDD-NOS and ADHD. My son has used Facilitated Communication (FC) via AAC software on his iPad for seven years. The Proposed ASHA Position Statement on Facilitated Communication (https://www.asha.org/uploadedFiles/Facilitated-Communication-Peer- Review.pdf and https://www.asha.org/peer-review/Proposed-ASHA-Position-Statement-Facilitated-Communication/) is offensive, false, and harmful, and as such, should be immediately withdrawn and discredited.

Contrary to the biased statements of the proposal that failed to consider input of those who use or aid others with facilitated communication, this method of communication has opened up my son’s world by providing him a true form of expression that is his “voice”. Often, he has expressed thoughts and beliefs that have been quite different than those of his facilitators, including myself and my wife, and he has been able to accurately demonstrate knowledge that we didn’t have. For example, I facilitated when he wrote a major section of a book report this year, including prompting him with why/how statements to encourage him to provide more details. My wife had read the book with him and was able to validate the accuracy of the book report. I, however, have never read the book, which makes it impossible for his typing to have been my thoughts. It was fully my son’s “voice”.

ASHA’s Ad Hoc Committee on Facilitated Communication defines facilitated communication as “a technique whereby individuals with disabilities and communication impairments allegedly select letters by typing on a keyboard while receiving physical support, emotional encouragement, and other communication supports from facilitators”. This very definition of facilitated communication demonstrates an inherent bias against this method of communication.

The supposed support behind this proposal is false and biased as demonstrated by direct evidence of those experienced in using or aiding others in this form of communication. My son’s communication journey over the past seven years, including with my wife and myself as facilitators, far outweighs any “literature reviews” and “peer studies”. Facilitated communication has provided him with focus to help overcome his ADHD and fine motor skills while using his AAC software. It has also helped him develop trust with specific individuals and belief in himself over a long period of time, thus opening him up to communicate deeper thoughts and trust to move to the next steps in his journey.

While facilitating with our son, we have learned many things about him that otherwise would never have been discovered. We learned of his love of baseball even though we aren’t sports fans ourselves. We learned of his shared desire to travel, including his interest in places that we have no or low desire to visit or had incorrectly assumed he would not be interested in. We learned about his anxieties upon graduating elementary school this year and why he was anxious. I could go on with many examples from over the past few years.

Bad facilitation should be handled through better training and oversight instead of the removal of facilitated communication. As for legal cases, lying under oath, false allegations and related offenses are crimes for a reason; however, speech itself has not been invalidated as a form of communication as a result.

The proposed recommendation on facilitated communication would be one of the most harmful things that my son and our family have experienced as it is a direct attempt to strip away and invalidate his human right of communication and, consequently, equal access to meaningful education. While my family will use facilitated communication regardless of this biased and misguided proposal, its recommendations would directly harm my son’s education and ability to become more independent if his school and therapists adopt this proposal. Additionally, it would hinder his progress toward independent communication and build on his existing anxieties and distrust by validating that “so called experts” don’t believe in him or his thoughts.

This position statement on facilitated communication should be immediately withdrawn and discredited. I will never strip away my son’s method of communication or discredit his tremendous advancements and prior communication due to this biased, harmful and offensive proposal, and neither should you.

Brian M. McKenna

June 2018

[REDACTED]

Dear ASHA leaders,

You have received many letters and messages from families, professionals, SLPs and teachers asking you to reject the proposed RPM position statement.

I, too, urge you to seriously reconsider your approach to creating guidelines for RPM. A true, meaningful position statement would be created with the input of a broad community: from providers of RPM teaching methods, from individuals with autism who have benefited from RPM, and from their families, friends, and teachers.

As it is now, the draft RPM statement suffers from factual errors about RPM, its approach, and its efficacy. These errors are evidence of the authors' one-sided view and lack of understanding of RPM. These issues with the document also highlight the lack of community input in creating this statement.

RPM teaches motor skills in a systematic way which allows individuals with autism to access academic information and gain many independent skills, including independent communication through pointing on a letterboard, typing on a keyboard, and verbal speech.

I personally know over 50 kids throughout our community who have benefited from RPM. RPM has given these non-speaking autism students access to grade-level academics, and many of these kids are college bound! There are currently two non-speaking students with autism at the University of California, Berkeley, a top-ranked university, who learned to communicate using letterboards and now are using iPads and laptops. These students are direct evidence that teaching methods like RPM lead to independent communication skills.

It will take many more years to fully understand autism and the brain. In the meantime, effective methods like RPM cannot be discounted simply because the explanations for how they work are immature. Instead, ASHA should be encouraging open-minded inquiry and investigation which includes all parties in an inclusive and open dialogue and research process.

Please remember ASHA's vision statement: "Making effective communication, a human right, accessible and achievable for all". You must include voices from the RPM community to make this happen.

Sincerely,

[REDACTED]

June 25, 2018

Katharine Anawalt

kanawalt@gmail.com

ASHA Peer Review on Proposed ASHA Position Statement: RPM

Link: https://www.asha.org/peer-review/Proposed-ASHA-Position- Statement-Rapid-Prompting-Method/

Do you agree with the proposed position that the use of RPM is not recommended? No.

Position Comments: A position with this much relevance and potential impact should emerge from a dialogue between a diverse group of professionals and practitioners as opposed to emerging from a singular and distinctly polemical view of RPM. ASHA approved, and is now, preparing to endorse the statement from a committee whose members are openly biased against both FC and RPM. The content of this report represents an imbalanced view that lacks a solid understanding of RPM, an approach with which none of the committee members has extensive practical experience. Facts have clearly been misconstrued to suit the already established opinions of the committee members. ASHA's position to "not recommend" RPM deters the likelihood of receiving adequate funding for future research examining its therapeutic benefit. To make the claim that any communication developed from RPM is not the voice of a person with a disability significantly limits the possibilities that are available to that individual. I have witnessed individuals successfully communicate information to trained RPM providers who have little to no information about the topic the RPM communicator is providing. In addition, I have witnessed individuals generalize their communication skills and unique personality across communication partners. This position severely restricts the cognitive and communication potential of individuals who have found success through RPM. It is irresponsible of ASHA to take such a harsh stance without any objective proof.

Do you have any comments about the RPM definition? If so, please provide below. The definition indicates a lack of care and understanding of RPM, especially since Soma Mukhopadhyay and RPM providers who underwent Soma's RPM training were not directly consulted on this definition. RPM has been used with nonspeaking and speaking individuals with autism. Furthermore, autism and intellectual disability should not go hand-in-hand as implied in the position's statement when it states that RPM is a "teaching and assistive method designed to establish and promote pointing-based textual communication in people with intellectual and developmental disabilities, usually autism." RPM providers assume the individual is capable of learning and responding to lesson plans. RPM realizes it may be difficult to demonstrate educational and literacy skills without a viable communication mode. RPM focuses on teaching individuals who are new to RPM how and what to choose, taking into account access, positioning, and learning styles (e.g., visual, auditory, tactile, kinesthetic). For a person new to RPM, beginner RPM lessons are introduced and the supports are modified depending on each individual learner.

2

Baselines are established and goals are set from those baselines. ASHA's position statement does not mention how the RPM provider works with the individual to emphasize and cultivate their maximum learning potential. If the individual struggles to demonstrate comprehension, the RPM provider teaches the concepts (which might include literacy skills) and/or presents the lesson in a variety of ways and, later, reviews the lesson. If it is clear the student is having trouble understanding an age-appropriate lesson, the RPM provider scales back so the student experiences success. If using a lesson that is not age appropriate, the RPM provider would still present the lesson being respectful of the individual’s age (e.g., use an age-appropriate tone). RPM is an academic method that aims to engage the learner at that instant of learning. New learning must take place in a session. RPM avoids repeatedly asking the same questions and teaching the same information in a rote manner.

Do you have any comments about the History section? If so, please provide below. This position statement neglects to mention that Soma Mukhopadhyay’s son, Tito Mukhopadhyay, an individual with autism who initially was severely non- communicative, now handwrites and types independently. Independence in this case means the communication display is not held by the RPM provider and verbal and gestural prompts have been faded. Tito Mukhopadhyay is just one of several individual who via RPM and the dedication of well-trained RPM providers has worked consistently through several skill levels to reach a significantly increased communicative independence. The history of RPM included in this position statement fails to mention that Ms. Mukhopadhyay conducts RPM Provider trainings. To maintain certification, RPM providers are required to abide by Ms. Mukhopadhyay’s RPM standards, particularly regarding lesson planning and RPM goals. They also must work with a variety of several individuals and seek advice from Soma on a regular basis, submitting videos of their work.

Comparison of RPM With FC (Paragraph and Table) Comments RPM is a separate technique. In RPM, the RPM provider might hold the letter board. This is significantly different from providing physical support. Holding the letter board this does not mean that the hands of the individual are being guided to the letters/text on a communication display. There is no evidence to support that the notion that RPM providers are speaking for the individuals with whom they work. In RPM, one goal is to have the individual using RPM to hold his/her own communication display or place the display flat on a desk in front of them. RPM also continually aims to decrease the prompts given. The committee’s statement indicates that the voices of individuals who use RPM and their measurable successes have not been factored into this demonstrably inaccurate position statement. The committee is, in fact, taking away the right of clients to choose how one wants to communicate, and effectively violating the communication rights of the very individuals they speciously claim to be defending.

3

Do you consider the information presented in the “Systematic Review of RPM” section of the statement to be current and suitable for the purposes of the position statement? The role of the “facilitator” is not to control the communication board. For example, numerous clients hold their own communication boards and choose to pick up their communication boards when they have something to say, effectively declaring through their own actions their ability and eagerness to communicate with RPM. How does the committee explain individuals who use RPM who have communicated information that was unknown to the communication partner? How do you explain individuals who use RPM that have communicated across several communication partners using their unique voice (i.e., syntax and manner in which they communicate is the same across communication partners)? The rate at which one achieves independence involves a variety of factors. RPM makes progress toward independence in several areas, one of which is communication. The position statement is shutting this door prematurely, particularly when it has only been around for less than two decades. RPM trainings did not start until 2005. ASHA, which prides itself on empirical research, should suggest that more research is needed before refuting this technique.

Do you agree with the Recommendations? NO

Recommendation Comments Multi-modal communication is always advised. RPM does not preclude other methods and the opportunity to access other interventions is not lost. A variety of methods are often attempted prior to and during the use of RPM. Clients continue to use RPM because they see benefits and progress over time. In not allowing the choice to use RPM, ASHA is taking away one's communication rights and stultifying the cognitive and communication potential of countless individuals. Even if there is no quantitative evidence that messages delivered by RPM reflect the voice of the person with a disability, that does not invalidate RPM. RPM is distinct from FC – it should not be discredited just because FC's efficacy requires further research. Client, parents, caregivers, teachers, professionals, and clients should have the opportunity to choose RPM, if they find it beneficial and of value to them.

What impact, if any, do you think the proposed position statement on RPM will have on your work or the work of others in supporting communication? It will erroneously make people afraid to try something. This position statement decreases opportunity to communicate, which goes against what speech-language therapy is all about.

Is there any other information that you need in order to be able to implement the ASHA RPM position statement? If so, write your information needs here: The position statement lacks understanding and knowledge of RPM. There is no input from clients or parents or professionals and their experience with RPM.

4

Additional Feedback: Evidence-based practice is the integration of best research evidence with clinical expertise and patient values. This position statement ignores two valuable components of evidence-based practice. The position statement does not include Ms. Mukhopadhyay's procedures for RPM training and certification standards. SLPs who plan to utilize RPM should abide by Ms. Mukhopadhyay's training standards and certification process and use best practice.

Failing a validation test of communication in an experimental condition does not mean that every time the individual communicates, his communication is false. Alternatively, passing a validation test of communication in an experimental condition does not mean that every time the individual communicates, his communication is true. Future research needs to understand that testing communication is complex. There must be an understanding of how communication works, particularly in RPM, prior to testing individuals.

Name: Katharine Anawalt, M.S. CCC-SLP Role: Speech-Language Pathologist Primary Employment Facility: Agency, organization, research facility (perhaps more aptly: Nonresidential health care facility – clinic, physician's office, etc.) How many years have you been practicing? 4-6 years Highest Education Level: Master's State of residence: California

The above comments on the review form were submitted to ASHA website on 06/25/18 at 3:30pm (EST).

June 2018

[REDACTED]

Dear ASHA leaders,

You have received many letters and messages from families, professionals, SLPs and teachers asking you to reject the proposed RPM position statement.

I, too, urge you to seriously reconsider your approach to creating guidelines for RPM. A true, meaningful position statement would be created with the input of a broad community: from providers of RPM teaching methods, from individuals with autism who have benefited from RPM, and from their families, friends, and teachers.

As it is now, the draft RPM statement suffers from factual errors about RPM, its approach, and its efficacy. These errors are evidence of the authors' one-sided view and lack of understanding of RPM. These issues with the document also highlight the lack of community input in creating this statement.

RPM teaches motor skills in a systematic way which allows individuals with autism to access academic information and gain many independent skills, including independent communication through pointing on a letterboard, typing on a keyboard, and verbal speech.

I personally know over 50 kids throughout our community who have benefited from RPM. RPM has given these non-speaking autism students access to grade-level academics, and many of these kids are college bound! There are currently two non-speaking students with autism at the University of California, Berkeley, a top-ranked university, who learned to communicate using letterboards and now are using iPads and laptops. These students are direct evidence that teaching methods like RPM lead to independent communication skills.

It will take many more years to fully understand autism and the brain. In the meantime, effective methods like RPM cannot be discounted simply because the explanations for how they work are immature. Instead, ASHA should be encouraging open-minded inquiry and investigation which includes all parties in an inclusive and open dialogue and research process.

Please remember ASHA's vision statement: "Making effective communication, a human right, accessible and achievable for all". You must include voices from the RPM community to make this happen.

Sincerely,

[REDACTED]

June 26, 2018

Hyam Bolande

habolande@gmail.com

Esteemed Board Members,

I am the parent of a non-speaking individual on the autism spectrum who is 10 years old at present. From the time of my son’s ASD diagnosis at age 3 until he began working with a letter board at age 8, we sought every intervention possible to teach him to communicate, to educate him, and to manage his behavioral challenges, including:

- Behavioral therapies such as ABA, TEACCH, and DIR-Floortime,
- Speech therapy,
- Occupational therapy,
- Restrictive diets and biomedical supplements.

Though it drove our family to exhaustion and near-poverty, none of these strenuous efforts over years made an appreciable impact on our son’s ability to communicate, integrate socially with family or friends, or progress academically. We observed frequent hints of the intelligence inside, but standardized tests and assessments made it impossible to clearly verify his level of cognitive or intellectual activity. He had difficulty to make his body respond to his will and thus demonstrate his understanding. As a result, in school and therapy, he was until the age of 8 repeating pre-school level lessons on topics such as basic shapes and colors, the alphabet and so on, over and over, without his teachers feeling he was ever mastering the material.

We began using letter board techniques similar to RPM at the age of 8, under the guidance of a trained practitioner, and it immediately began to transform my son’s life and his family’s. By using the techniques, we for the first time observed proof positive that my son had been absorbing and retaining knowledge his entire life. He had an age-appropriate vocabulary, and was able to do academic work (math, English, science) at his age level. Furthermore, he was able to “join” his family for the first time, clearly sharing his feelings, his needs, his preferences and even his sense of humor.

At school, it was not difficult to convince administrators and teachers of his newfound communication ability – they had long been frustrated and were all to eager to finally work with him in earnest. Today, at age 10, my son is preparing to enter the 5th grade, and his school has accepted that he is ready for that grade’s level work in most subjects but advanced 6th-grade material in math and science. He is often able to arrive at working solutions to math problems and computer-programming problems that are not readily apparent to his communication partners and teachers.

My son is looking forward to graduating from high school and attending university as a non-speaking person who spells to communicate through his index finger. Although he is still using a letter board today, he is advancing rapidly toward the goal of using a hardware or touch-screen keyboard to form his words and sentences (AAC) more independently. To lose his preferred method of communication would have a catastrophic impact on his life, erasing all these life-changing gains. Furthermore, it would rob him of the prospect of becoming a productive member of society in the future.

I am writing to you today regarding two proposed position statements that were recently posted on the ASHA website for public comment, statements that recommend against the use of two particular methodologies used to teach individuals with speech-related disorders to communicate using letterboards and keyboards, namely RPM and FC.

The drafting process for these statements has displayed bias of such a serious nature that I decided that participating in the standard public-comment process that just closed would be of no use—input such as my own would most likely be ignored. Therefore, I am writing directly to you, the ASHA Board, instead, to urge you to withdraw the proposed statements. The reasons for my concern are below:

First, the statements' recommendations are disconnected logically from their factual premise, which is that the two methodologies have yet to undergo rigorous experimental research to confirm their efficacy. Based on that premise, the scientific next step would be to recommend further research and evaluation of the methodologies—not to recommend halting their use entirely and preventing any such research from taking place.

Second, an ASHA position statement recommending against the use of particular communication-related methodologies could contravene legal rights established under the Americans with Disabilities Act. The ADA requires public entities like schools to support an individual's preferred method of communication, except in extenuating circumstances. 28 C.F.R. § 35.160. As such, ASHA's proposed recommendation risks putting its members and their employers in the position of having to choose between complying with the recommendation or the law.

Third, the premise underlying the proposed statements—that individuals who use these methods are incapable of the complex thoughts that they express—is unsupported and prejudiced. The committee is recommending to block the very research that is needed to validate such a point and thus is adopting a discriminatory position. Given the ADA, the burden of proof for depriving a citizen of his/her preferred method of communication should be extremely high.

Finally, ASHA's process lacked transparency, openness and a diversity of inputs. We are concerned that the Committee's inquiries were neither open nor unbiased, leading to a pre-determined outcome.

- The Committee did not allow users or professionals (including ASHA members) with direct experience in either methodology to join, and failed to solicit the perspectives of such users/professionals at any point during its year-long review process.

- Multiple members of the Committee have a documented history of advocating against these methods that predates the review. In fact, the Committee cites its members' own work as support for its proposed statements.

If ASHA were to authorize recommendations that lack supporting evidence, promote prejudice and potentially lead to potential civil rights violations, it would not only harm individuals with disabilities but the Association's reputation. ASHA's vision statement is, "Making effective communication a human right, accessible and achievable for all."

I urge you, therefore, to withdraw the proposed position statements from further consideration and—as soon as possible—launch a deeper, more open and unbiased inquiry on this subject, one that is important and life-changing.

Sincerely,

Hyam A. Bolande

June 26, 2018

Josha Smith

lolacoolj@gmail.com

We are writing to you today in response to the draft position statements issued by ASHA's Ad Hoc Committee on Facilitated Communication (FC) and Rapid Prompting Method (RPM). We are the family of a 21 year old autistic young man whose speech is unreliable and whose body movements lack intention.

Responding as mother to my adult autistic son and as a licensed special education teacher, I would like to urge you to reconsider such a drastic position. I would expect from a credentialing organization such as ASHA an invitation for further study, perhaps, but not the extremely biased, unfounded, and sometimes inaccurate statements I see in the draft.

After years of traditional speech therapy and other therapies, my son's speech remains unreliable and below grade level. It was with Rapid Prompting Method as an educational tool that he became able to move his body with purpose to respond, by making choices through pointing, as he listened to age appropriate academic lessons. Like with other approaches, this required prompting at first. Those prompts were faded as he made the choices himself with his own intentional pointing. Finally! After former failed programs, attempted to teach pointing, through RPM, he was now pointing in response to age appropriate academic lessons! Subsequently, he was prompted to point to letters on a letter board held within his visual field. Again, fading the prompts as he gained more and more control over his body. I would like to reiterate that prompting is not isolated to RPM. How many prompts do SLP's use with children to help them gain success? As many as needed, I would hope. This is simply good teaching. RPM is no different.

Finally, with RPM, our son is able to match what he says with what he is spelling on the letter board. SPEECH! Purposeful, accurate, reliable speech is resulting from his efforts to gain purposeful control over his movements, including those required for speech. The letter board is a tool. We are using it to move toward autonomy and purposeful movement and finding more success with RPM than with any other approach we have tried. Our son has his own wit and personality and intelligence. He is a successful university student who writes essays and participates in online courses with other students and professors who see his potential and hear his voice.

I, personally, considered no response to the position statement, as I think that while it is a disappointment, it doesn't change what I know to be true. After all, I am able to make my own choices as is pointed out in the statement. I reconsidered, however, as I thought of other students who might never take a look at RPM because of a harsh, blanket statement like the one presented. As an educator, I cringe to think of anyone not having the same opportunities as my son, and can only hope that they find a speech therapist who has discovered the tool of RPM at an earlier age than my own son. What a tragedy not to utilize every tool available!

Furthermore, we are disappointed to realize that the group of individuals ASHA selected to develop this position statement includes no one with direct experience in the methodologies in question. The Ad Hoc Committee is a group of individuals that have made publicly documented, derogatory remarks about disabled individuals who use these methods; and have personally attacked those who have supported them. This position statement was clearly not drafted by unbiased individuals, and multiple viewpoints were not considered in reaching these extreme conclusions.

We stand with our autistic son, asking for the following: 1) that the proposed statements regarding spelled communication be withdrawn; and 2) that ASHA issue a formal apology for the damage that has been done by these statements to the civil rights of individuals with disabilities.

As the brother of a man with autism, and a witness to the effects and applications of the Rapid Prompting Method (RPM), I would like to state that RPM is the most effective and astonishing practice that I have ever perceived. I have seen my brother go through tremendous change just in the last few years, progressing further than with any other method we have used before. He has gained much more control, more communication, more happiness, and more independence. I beg of you, do not take this opportunity away from others. People like myself want communication with their siblings. Communication is key to every relationship, and RPM provides that communication. As a man who has found a friend he never knew he had, do not take this opportunity away from others. We need our loved ones. And they need us.

Writing as the sister of a man affected by autism, and as a scientist: in response to ASHA's stated position on Rapid Prompting Method (RPM).

Undoubtedly, the goal of ASHA is to endorse therapeutic techniques so that any individual may have a chance at freely expressing themselves through speech and language, regardless of disability. This makes ASHA's position statement on RPM disappointing. I have the unique opportunity to watch my brother make tremendous progress in his autonomy through use of RPM, and believe this method of expression should be an available and encouraged option for those who suffer similarly to my brother. Before beginning RPM, my brother spent 18 years in various types of intensive speech and behavior therapies that progressed his expression only to the point of movie lines from kid's shows and wild bodily movements that were uncontrolled and occasionally hazardous. The first time he tried RPM (at 18 years old), his mouth was screaming obscenities but he spelled to my mother "It's nice to finally meet you," and since then his world has completely turned around. He is able to participate in higher education, make decisions (i.e. clothing and style, restaurant preference, movie nights, etc), express feelings, and hold conversations; all of these would have never been a possibility without RPM.

The main quoted evidence against RPM in ASHA's statement involves the existence of a communication method called Facilitated Communication (FC), which is commonly accepted as a junk science. RPM does hold similarities with FC, but there are important differences that should be highlighted, such as the following:

1) RPM facilitators do not guide the hand or limbs of the individual like FC facilitators. Depending on the individual, brief touches or prompts may be given to help keep them on task, especially when first learning how to communicate using the method. Rather than directly touching and guiding the hand of the individual, RPM facilitators hold an alphabet board in front of the individual, adjusting to provide ease of access to the general area as indicated by the individual.

2) Unlike FC, the goal of RPM aims to achieve open-ended verbal communication (when applicable given the disability) by using techniques designed to "fade out" the letter board and promote verbal autonomy. Such techniques typically rule out facilitator involvement, as only the subject can know to which letters they are pointing.

3) RPM provides age-appropriate education to keep the individual on task as well as instruct the individual on a topic.

These points display the fundamental difference between FC and RPM: long term independent communication, unaided by a guiding hand. Using FC as evidence for RPM's validity just because they both involve an individual pointing at letters on a board with a facilitator is a hasty generalization. While there is currently no peer reviewed literature behind (or against) RPM, it should not be disregarded simply due to its similarity to FC and should instead be researched more thoroughly before an official position can be reached.

Suggesting that those who use spelled communication are not independently communicating is a violation of the civil rights of these individuals. Therefore, I agree with my brother that an apology be issued, not only for those whose autonomy is questioned by ASHA's allegations against spelled communication, but also for all who suffer from disabilities that prevent them from free, neurotypical expression. ASHA's statement does not assume that individuals suffering from disabilities are mentally competent (statements such as, "The level of skill proficiency claimed to be a result of RPM is a level that educational and psychological research suggests is unlikely (Lang, Harbison, Travers, & Todd, 2014)."), and it restricts access to all potentially useful communication techniques by discrediting RPM despite the lack of evidence to support this claim. ASHA must consider pursuing further research into RPM itself before making their official position on the subject.

June 27, 2018

Cathie Davies

cathiedavies@optusnet.com.au

The draft FC Position Statement is antithetical to Evidence Based Practice (EBP)
ASHA professes to “incorporate the principles of evidence-based practice in clinical decision making”. In this approach: “current, high-quality research evidence is integrated with practitioner expertise and client preferences and values into the process of making clinical decisions” (https://www.asha.org/policy/PS2005-00221/).

There is, however, very limited evidence of commitment to an Evidence Based Practice (EBP) approach in the draft Position Statement on FC.

High-quality research evidence

The draft statement repeats, at least six times, the accusation that there is no scientific evidence supporting FC. No definition of “scientific evidence” is provided. The only empirical study of FC cited by the draft is the ISAAC review (Schlosser et al. 2014).

The accusation of “no scientific evidence” is extremely misleading:
As I have outlined in my “Systematic Review comments”, submitted via your website, Schlosser et al. (2014) is a seriously flawed review. It would not be admitted as evidence under the hierarchy of evidence reproduced on ASHA’s website (https://www.asha.org/Research/EBP/Assessing-the-Evidence/), which rates “meta-analysis of randomized controlled trials” at the highest level of “external scientific evidence” (Level Ia), but makes no reference to narrative reviews of quasi-experimental studies.

The “scientific evidence” referred to in the draft position statement is drawn from quasi-experimental studies. The ASHA hierarchy of evidence identifies well designed quasi-experimental studies as research evidence level IIb. However, neither Schlosser et al. (2014) nor the ASHA draft Position Paper examines the studies for quality or validity. As explained in my “Systematic Review comments” (submitted via your website), the validity of the outcome measure has not been established – a major flaw among many inherent in the message passing studies.

Despite its flaws, Schlosser et al. (2014) acknowledges the existence of qualitative and mixed design studies supportive of FC. It subsequently excludes them with only the most cursory consideration. (See “Systematic Review comments”, submitted via your website.) In contrast, the ASHA draft Position Paper denies the existence of such studies. Both approaches are entirely unjustified. The hierarchy of evidence on ASHA’s website makes it clear that well designed non-experimental studies do qualify as level III research evidence.

Having ignored the existence of level III evidence, the draft position statement makes much of the fact that "as many as 16 other national and 131 international professional organization statements" are consistent with the proposed position. The hierarchy of evidence places "expert committee report, consensus conference, clinical experience of respected authorities" as the lowest form of research evidence - level IV, below the ignored studies at level III.

ASHA's FC committee has clearly taken a highly selective approach to the external scientific evidence.

Practitioner Expertise

With regard to clinician generated evidence, the following points may be made:
Respect for clinical judgement, based on training and experience, is a central tenet of EBP. For example, as noted in the context of Evidence-Based Medicine (EBM): "clinical expertise is the crucial element that separates evidence-based medicine from cookbook medicine and the mindless application of rules and guidelines" (Haynes, Sacket, Gray, Cook, & Guyatt, p197). Similarly, in the context of evidence-based practice in psychology (EBPP): "Research suggests that sensitivity and flexibility in the administration of therapeutic interventions produces better outcomes than rigid application of manuals or principles" (American Psychological Association Presidential Task Force on Evidence-Based Practice, 2006, p.278).

At line 70, the ASHA draft position statement refers to "peer-reviewed studies and clinical assessments". It is clear from the context that "clinical assessments" refers to message passing tests in clinical settings. The validity of message passing as a measure of communicative competence has not been established for either clinical or experimental settings. There are good reasons to question this outcome measure, as elaborated in my "Systematic Review comments" (submitted via your website).

The hierarchy reproduced on the ASHA website refers only to external research evidence. A model of EBP developed for SLPs (Gillam & Gillam, 2006) suggests a parallel hierarchy for internal evidence, as an aid to integrating the three EBP domains. This model rates clinician generated evidence at the same level as published case studies, and more highly than "expert opinion" such as Position Statements. This would suggest that the full range of clinician generated evidence, not only the potentially invalid message passing tests, should be considered. Clinician generated evidence has been excluded from consideration by Schlosser et al. (2014) and (with the exception of line 70) the ASHA draft report.

It must be recognized that, should the draft Position Statement be adopted, clinical decisions will be taken out of SLPs' hands. The principal that SLPs are autonomous professionals will be abandoned, along with any respect for their professional judgment in identifying the most appropriate intervention for their clients.

Client Preferences and Values

ASHA refers to the third domain of EBP as "client preferences and values". One member of ASHA's FC committee has previously noted that:

In AAC we have a longstanding awareness of the crucial role of the individual using AAC and other relevant stakeholders in decision-making and evaluating the impact of our services and interventions. Hence, the viewpoints, preferences, concerns and expectations of those who directly or indirectly control the viability of an assessment or intervention (e.g. individuals using AAC, family members, caregivers, friends etc.) need to be integrated with clinical experience and research evidence (Schlosser, 2004)

Professor Schlosser even goes so far as to suggest that: “my colleagues and I have argued the primacy of relevant stakeholder perspectives in moving this integration process to decision-making” (Schlosser, 2004).

Significant as this statement is, the reference to stakeholders’ perspectives may over-emphasize client’s attitudes at the expense of the physical, sensory, neurological medical or other differences that may contribute to their complex communication needs. In Australia, Speech Pathology Australia’s (SPA’s) Clinical Guideline for AAC adopts the Transdisciplinary model of EBP (Satterfield, Spring, Brownson, Mullen, Newhouse, Walker, & Whitlock, 2009), in which the “client” domain has become “client’s/ population’s characteristics, state, needs, values and preferences” (Satterfield et al, 2009, p382). The importance of the clinical relationship in identifying and responding to the highly individual needs of clients – particularly those with complex communication needs - cannot be overstated.

The draft Position Statement on FC would, however, severely restrict ASHA members’ discretion and ability to exercise their professional judgment in selecting the most appropriate treatment for their clients.

It must also be noted that the voices of clients and other direct stakeholders in the FC debate have been totally excluded from consideration by the ASHA FC committee.

June 28, 2018

Christine Kane

cdkane@gmail.com

My grandson, who will be turning 13 in three weeks, has autism and is non-speaking. He had every therapy available to give him the ability to communicate verbally, all to no avail.

When he was 10 his mother read about the use of letter boards and researched it. Both she and my grandson were evaluated for its effectiveness and it was felt they were good candidates. My grandson now communicates with me using the “board” and we have marvelous conversations. He is a brilliant young man and has told me on numerous occasions, how discouraged and frustrated he was for years that he couldn’t make his wants and needs known, as well as carry on conversations about things that interested him. This was authentically him communicating with me.

I’m familiar with the fact that you don’t believe in the efficacy of this method, but I can tell you that at least for my grandson it works. The joy it has brought to him is unimaginable and I can’t fathom how his mother must have felt the first time he told her how much he loved her.

I ask that you reconsider your position. The use of letter boards may not work for everyone, but I know one young man who it does work for. To take away his ability to communicate with society as a whole is bordering on criminal. How my grandson would feel if you took that away from him I can’t imagine. Put yourself in his shoes.

Christine Kane
Cocoa, Florida 32927

June 29, 2018

Sarah Jones

sajonest42ne1@yahoo.com

If autistics have a unique language pattern typing, does this support the legitimacy of facilitated communication? A scientific study in Italy and autistic individuals in the United States offer compelling evidence.

Does Autism Have a Second Language?

“There can be a misconception that because neuro-typicals and autistics use the same vocabulary that we speak the same language." - S. A. Jones

In this series we explore how typicals can develop more meaningful, authentic relationships with autistics by learning about autism, from an autistic perspective.

AUTISM AS A SECOND LANGUAGE
by S. A. Jones c. 2009, 2010

There can be a misconception that because neuro-typicals and autistics speak the same vocabulary that we speak the same language.

In the book “Reflections of Self” by Sondra Williams, who is autistic, she shares what the English language is like for her on page 18:

“I have developed a seemingly odd way of being in words that is like its own dialect. This unique language pattern emerged early in my development. My ‘own’ language is natural to me, and even though I have been exposed to the English language all my life, it is un-natural to me. I have a hard time understanding why English words are spoken in this fashion, yet I have learned the English language to a degree. I can use it functionally in some environments where I know its use is expected, but cannot sustain it for long. I use the English language within my work setting, but to me this is very uncomfortable. Unfortunately when I use my own dialect in my speaking or writing, many people assume I am intellectually impaired. Once they take the time to know me, they realize this isn't true.

"Here is an example of my unique dialect, describing my experience as a presenter at an event for educators:

Many to say never to heared words that are of like the way I to be speak, but those who to taked the time to listen to the thinking of the words, they to learned to know the real of me. Another things is often I to be to forget I to be talking to a large groupof peoples and often become rapid in my words and or monotoned because I to be so much into my scripts that I to do it mechanically. I to not be away to be do this and be to get of stuck in this at times speaking ever so fast and not giving people time to hear it. I to practice much in my work although I to be lack body gestures and eye contact I to seem to be of still able to get my thinking out to others. I to often make some to be in tears at my speaking from the things I to share and this to confuses me about which words or why my words caused of them tears or sad to the peoples. I to have been to get peoples to stand up after I to be to speaked and I to lacked knowing of this gesture, but a friend telled me what this to means too. I to now know that the word 'standing ovations' to me. I to feel happy some people can see Sondra expressed in such a way they to validate of my words this way."

(For more information about Sondra Williams and her book go to: www.thegraycenter.com.)

SCIENTISTS IN ITALY have been mapping the structure of Autistic writing with Italian subjects (see article, attached, below; "Moved deeply I am"). They have found similarities in how autistics write, which differ from how typicals write and talk, using the same vocabulary or language:

"Preliminary results [show] that autistics actually use a special style of writing; this finding supports the hypothesis that texts are the fruit of individual production of autistic subjects, not inevitably influenced by facilitators."

This is an important discovery because it validates that this form of communication is uniquely autistic, as opposed to being the writing style of a neuro-typical facilitator assisting the autistic.

Interestingly, this study observed with its autistic and typical subjects that:

"The two vocabularies have in common 1,950 word-types. This intersection set represents 52.5% of the facilitators' vocabulary (1, 950 word-types out of 3,714) and only 37.0% of the vocabulary of the autistic subjects (1,950 out of 5,264). Facilitators use 1,764 word-types never used by autistic subjects (equal to remaining 47.5% of the vocabulary), whereas autistic subjects put in their texts 3,315 word-types never used by facilitators (equal to 63.0%)."

The same language, the same vocabulary perhaps intersect. But form and structure of communication may differ greatly between typicals and autistics. Therefore, to function in the typical world, autistics may need to adapt to the ‘standard’ forms of typical speaking and writing, even if it is their not their inherent or first inclination.

(Tuzzi, A., Cemin, M. Castagna, M. (2004) “Moved deeply I am” Autistic language in texts produced with FC. Journees internationals d’Analyse statistique des Donnees Textuelleds, 7, 1-9. Google "Moved Deeply I am” to access a .pdf copy of the Italian study.)

Questions to the Autistic Reader: How does this topic resonate with you? Can you relate to Sondra Williams’ way of writing? Do you have to modify the way you communicate to make what you write or say sound ‘typical’?

Questions for the Neuro-Typical Reader: Have you observed a ‘different’ way of writing that has consistencies and predictable patterns, when reading and/or listening to autistics speaking and writing for meaning?

June 30, 2018

Selena Pistoresi

info@cultivatemusicstudio.com

Cultivate Music Studio

5145 Stevens Creek Blvd. Suite 220
Santa Clara, CA 95051
559.706.6184
info@cultivatemusicstudio.com

To Whom It May Concern:

I am the founder, director, and head teacher at a music studio in the South SF Bay Area that primarily serves students with special needs. Over half of my 50 students are nonspeaking or minimally verbal. At my previous position at a nonprofit inclusion school in the Bay Area, I observed several other interventions such as AACs and speech therapy sessions with licensed SLPs as well as Applied Behavior Analysis. It was at this school that I was introduced to RPM by a trained provider and first started observing the benefits of RPM with dozens of students for whom all other communication approaches had failed or made very little progress. I saw how RPM, when implemented in its true form, could provide access to communication to students on a level that was previously thought impossible. Most importantly, I saw some licensed SLPs come to see the benefits of RPM and use it during sessions to further students' communication progress as they are expected to do.

After observing several students, over the course of a few years, go from making "paper choices" with prompts to typing independently on a keyboard with no prompting whatsoever, I decided to pursue more training in RPM. I now use it in my studio (with students who also use it at home) to teach music theory, history, and technique. Students who can only verbalize words like "break please," "no," or "gummy bears" are able to type answers to higher level music theory questions and show critical thinking about the impact of music on society. Preventing my students from being able to access their preferred communication method and demonstrate grade-level knowledge about subjects that interest them would be unthinkable and completely unethical.

I am disappointed and concerned that the Ad hoc Committee poised to condemn RPM has refused to consider input or evidence from RPM users and ASHA members with experience in the methodology. Policy decisions of this magnitude should involve careful and unbiased examination of the evidence. I fail to see how the current Committee is unbiased since it comprises individuals with histories of personally attacking these methodologies in the interest of promoting their own preferred methodologies. The Committee's illogical, one-sided, and baseless conclusions suggest that some members sought this platform to advance personal agendas to end communication choice. In my view, the benefits of RPM are indisputable and should at the very least be examined with true academic rigor before being condemned.

If ASHA is indeed committed to "making effective communication, a human right, accessible and achievable for all," then I should think the organization would conduct or support true research into such a widely accepted and promising method, instead of issuing statements that would surely impede that research. I encourage ASHA to withdraw the proposed statements and issue a formal apology for the damage that has already been done to the civil rights of individuals with disabilities by the Ad Hoc Committee.

Sincerely,

Selena Pistoresi
Director and Piano Teacher
Cultivate Music Studio

July 2, 2018

Juan A Camarena

camarenajp99@yahoo.com

Dear ASHA,

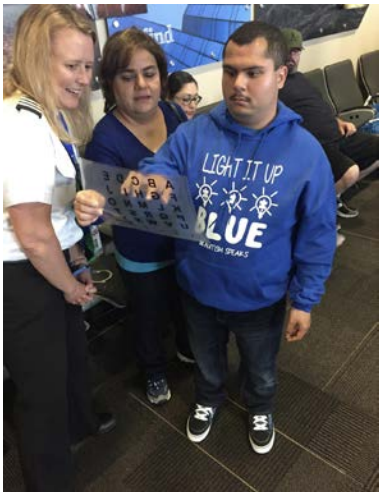
I’m a boy, who is able to communicate using the letter board. I’m not a stupid person who is NOT mentally retarded, because I’m not able to communicate, so

I’m a guy who deserves respect no meaning to insulte any one to communicates in any way. “ I’m a free person thanks to RPM.” I’m not superior to anyone.

“ I’m a human who deserves respect to my life, and to my way to express”.

Sincerely and Respectfully,

Juan Pablo Camarena.



July 2, 2018

June E. Bascom

June.Bascom@vermont.gov

I am a professional who has worked in the field of developmental disabilities for thirty-five years. I was first introduced to facilitated communication (FC) around 1990. Since then I have seen first-hand how FC has changed the lives of countless people who otherwise would have had no meaningful communication. I have seen people gain confidence and self-respect, pursue their dreams and discover their passions. I have seen people develop deep, personal and fulfilling relationships once they were able to express themselves. For one man, it was life changing the first time he was able to tell his mother he loved her. For another it was when he graduated collage with honors. I know high school students who became poets, telling in heart wrenching honesty about what it is like living with autism. Another is a successful painter while another will soon be officiating the wedding of a friend.

Many with debilitating disabilities are able to begin the long journey of creating a life without constant suffering once they can express to others what they are experiencing and how to alter their environment and interactions with others. Through dialog; unconditional support of friends, family and professionals; and great personal courage, many have discovered and fostered their best selves. Perhaps most telling, through supported typing, people have explored their most disruptive and harmful behaviors and through extraordinary effort learned how to calm themselves and discovered new ways to be in the world. It is these dramatic changes in people's behavior and their lives that is undisputable in terms of the efficacy of FC and the most damning in terms of the proposed ASHA position statement.

This ASHA position statement violates the most fundamental tenant of disability rights – the "Presumption of Competence". It is shameful that a professional organization the likes of ASHA is choosing to willfully ignore the overwhelming and incontrovertible evidence that FC is a valid means of communication support. There are both qualitative and quantitative peer reviewed studies that have been published that indicate that FC is a viable means of communication support. The ASHA position statement reads not as a professional and well considered document but more a repetitive rant that is an absolute, out-of-hand dismissal of a verifiable communication method without taking into consideration any of the existing evidence supporting FC.

The ASHA position statement says "It must not be assumed that messages delivered via FC or any other facilitator-dependent technique…reflect the voice of the person with a disability" (lines 56-58). That is absolutely correct. To do so would be irresponsible as there are reliable techniques such as "message passing" that must be used to verify if it is the person's words that are being typed vs. that of the facilitator. Qualitative evidence abounds in everyday practice of FC: people have eventually learned to type independently, read their typing and accurately tell of events unknown to the facilitator.

On the other hand, just like all medical protocols do not work for every patient, FC does not work for all individuals with limited communication. Like many behavioral interventions, individuals providing facilitation must be well trained and supervised in the technique and follow the long-established protocols and best practices. When friends, family and professionals do not follow accepted FC standards, it can lead to poor and inconsistent practice which may ultimately result in inadequate support and facilitator influence. Virtually all the studies (most which are quite old by now) that the position statement indicates have “discredited” FC used facilitation techniques that do not meet the FC standards resulting in subjects being negatively influenced by their facilitators. The fact that those published studies were repeated and the methodology not thoughtfully examined is poor and irresponsible research. This has tragically led to people losing their one and only method of communication, virtually silencing them. How does this maligning of a technique that has successfully brought voice to those who had been voiceless align with the National Joint Committee for the Communication Needs of Persons with Severe Disabilities “Communication Bill of Rights” and the “United Nations Convention of the Rights of Person’s with Disabilities”?

It is with the rights of all people with disabilities in mind that the misguided ASHA position statement must be rejected.

<u>Question asking about definition of FC</u>
It is completely inaccurate and does not reflect what it is or how it is used.

<u>Question about how position statement should be used</u>
The position statement should not be ratified or used under any circumstances.

<u>Question asking for additional feedback</u>
Lines 36-38 – False allegations of abuse happen without the use FC as well. It is imperative of investigators of abuse to use multiple methods to determine if an allegation is founded. It is unconscionable to take away a person’s only means of communication when that person has made an allegation of abuse, whether the allegation is true or not.

June E. Bascom
Developmental Disabilities Services Division, DAIL
280 State Drive
Waterbury, VT 05671-2030
802-241-0352 – Phone
802-241-0410 – Fax

July 18, 2018

Pamela Driscoll

As a Special Education Teacher, I did not believe in Facilitated Communication because that is what I was taught in college. Five years ago, I was desperate for help with my own son's behavior and frustration with not being understood. I knew he would not be able to participate in community activities without improvement in his behavior.

At age 25, he was introduced to FC. It still took months for me to realize/believe that my son had learned spelling, reading and a lot of information, that he had no way of showing us. He remembered things that should not have been discussed in front of him. He grasped major Christian concepts from listening to years of sermons and Sunday School presentations. He had a manner of using sentences that portrayed a unique, sensitive, polite, individual. He has told us that his behavior and his speech are "my worst enemies" because those movements and words are not communicating the "real" him.

He continually thanks the people who introduced him to FC and those who are helping him to be more and more independent with his typing, for giving him a way of showing that he is smart and of showing what he wants, thinks and feels. His insight has helped us to learn more effective ways of dealing with his behavior.

"Presuming competence" means something to us. After 25 years of not presuming competence, it is hard to change and I become quite sad when I think of all the discussions we could have had and how hard it must have been to never be understood. I am so thankful to Peggy, Darlene and Cheyanne for starting us on this journey and walking alongside us, for introducing me to my son. It is devastating to think how many children and adults will never find a way of communicating effectively, whose parents will never really know them and for whom the label intellectual disability is not only inaccurate, but insulting. Facilitated communication/supported typing is real. Just ask all those who now type independently. Just ask my son.
