TASH

Equity, Opportunity, and Inclusion for People with Disabilities since 1975

The Continued Debate about Facilitated Communication: A Response from TASH's Executive Director and President of the TASH Board

The value and utility of facilitated communication (FC)—and TASH's relationship to it—has been debated now for over 20 years. As a result, a number of TASH members have taken strident positions, either critical of FC or in favor of its use. Because TASH has remained intact and resolute in its commitment to achieve its mission, we continue to take on tough issues that sometimes cause tension and division in the organization in order to arrive at important contributions to the quality of life of people with disabilities. This is a role we must continue to play. We believe it is appropriate now to clarify TASH's position on FC.

The Fall issue of *Research and Practice for Persons with Severe Disabilities* (Volume 39, Number 3) was a special issue about FC. The intent was to provide an opportunity for TASH members to share their opinions and perspectives about FC, relative to the current research available on the subject (RPSD is a research journal). There were two calls for papers and opinions from researchers who were either in favor of or critical of FC were sought. Four papers were submitted—three critical of FC and one advocating for its use. As the editor Martin Agran shared with us, he had hoped that there would be a balanced perspective—in fact, a promised paper that supported FC was never received, hence the imbalance. This may be an accurate representation of the articles submitted for publication, but it may not be representative of the sentiments in the field, or of the full range of TASH members.

In one article specific individuals with severe disabilities were named. It has come to our attention that a number of TASH members were offended by this mention and thought that the authors were questioning these individuals' independence in communication. The editor has defended the authors' use of names by insisting that (a) no personal insult was intended; (b) the intent was to criticize some of FC's claims when there were limited data to support them; and (c) the individuals named were very much in the public domain and, as such, this visibility exposes them to discussion. We will leave it up to TASH members to decide for themselves if they believe such personal references were warranted. In response, TASH will now include an ethics statement in RPSD and at www.tash.org to guide future authors. TASH also formally apologizes to these individuals for any harm caused by the references made to them.

As a matter of policy, one article appears to reflect an inaccurate representation of TASH's official position. The TASH board approved an updated resolution in 2008 on the Right to Communicate. This resolution promotes no particular method of AAC. However, it does uphold an individual's right to use their preferred method of communication.

All of the articles were written by well-established researchers and nationally recognized leaders in the area of severe disabilities, and we are not criticizing their professional credibility. That said, three of the four articles were highly critical of FC. We trust that, despite the acrimonious tone of these articles, critics (and advocates) in the future maintain a respectful tone for opposing opinions.

There is no question that TASH members value research and to TASH's credit, we have encouraged and supported varying research methodologies and perspectives. The organization was founded on a belief that research should drive advocacy – and we live by that today. The research TASH members have conducted has shaped the field and provided credibility to the values we uphold. The marriage of research and values has been a singular advance in the professions serving people with severe disabilities and one of TASH's greatest contributions. In one respect, the FC argument involves one undesired complication. Critics of FC have largely been quantitative researchers and proponents for FC have been qualitative researchers. We trust that we are not seeing a competition here between these two approaches. Both approaches have their respective value and are used to address different kinds of questions. Again, respect for opposing opinions—in this case, methodologies—is encouraged.

There is no question that a major criticism of FC is the risk of harm due to the influence over authorship by the facilitator. The risk was thoroughly described in the RPSD articles. This is a serious concern. However, we must have perspective about risk in terms of interventions – virtually no intervention is risk-free. Therefore, important questions are how to mitigate risk through improved methodology – and how to fully inform parents and people with disabilities about potential risks. Denying these risks or making excuses about them does more harm than good. Both sides need to acknowledge this problem.

We know that too many students with severe disabilities are not afforded the supports they need to effectively communicate, severely limiting their academic and behavioral success. In a recent study, 30% of students taking an alternate assessment were reported to be pre-literate, and of those students, more than 50% had no communication support (Kearns, Towles-Reeves, Kleinert, H. & Kleinert, J., Thomas, M. (2011). Alternate Achievement Standards Assessments: Understanding the Student Population. Journal of Special Education.) Once communication intervention is provided, Rowland and Schwiegert (2000) found that most students with severe disabilities experienced success with as little as 15 minutes per day of instruction over an average of 6.5 months.

The reasons for this egregious lack of communication supports are numerous and we need to do everything we can to close this gap with meaningful services and supports. We will leave it up to you to determine if, given the lack of communication supports available to people with severe disabilities, FC should be used or not. We believe we need to move beyond dug-in positions and address the following questions, posed by the TASH Inclusive Education Committee Research Agenda:

- What strategies and interventions designed to increase communicative competence are most effective for children with severe disabilities and how do we make those strategies and interventions available in general education settings?
- How does access to AAC increase communication skills of pre-symbolic and emerging communicators?
- What is the decision–making process school-based teams are using when considering the communicative needs of students with significant disabilities?
- How has technology changed the access to AAC for students with significant disabilities (e.g., iPad, iPod) who participate in the general curriculum in inclusive settings?
- What is the impact of access and competence in communication methods to the long-term outcomes for students with significant disabilities, such as quality of life, patterns of activity, social relationships and employment?
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As discussed in the special issue of RPSD, FC has had a controversial past; is not considered evidence-based by many researchers; and a potential for harm may exist. That said, it appears to have had limited success with some individuals in some situations and the field needs at least to be open to discussion about its potential utility. With that information, parents and people with disabilities themselves can decide for themselves what they wish to do.

Our personal opinion, based on decades working professionally in the field and as family members, is that the inability to communicate is a devastating reality for far too many. People who cannot express themselves are not safe in the world, and their communication needs must be addressed. Let us continue to discuss how we can address this critical need, how we can select the most effective augmentative communication strategies, and how we must keep the table open to diverse approaches.

TASH currently has no official position on FC, although we are firm in our belief that people have the right to communicate in the way they find most effective. No doubt some TASH members may feel that TASH should take a position on this practice. Given the diverse membership of TASH, we are not sure this would serve the organization well. We do this because it's the right thing to do in the face of a great unmet need. Let us continue to discuss this issue and continue to find common cause in improving the quality of life for people with severe disabilities.

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