

“Attention: Myth Follows!” Facilitated Communication, Parent and Professional Attitudes
towards Evidence-based Practice, and the Power of Misinformation

David Trembath

Menzies Health Institute Queensland, Griffith University

Jessica Paynter

AEIOU Foundation

Deb Keen

Autism Centre of Excellence, Griffith University

Ullrich K. H. Ecker

School of Psychology, University of Western Australia

Key words: facilitated communication, parent training, misinformation, evidence-based practice

Correspondence:

David Trembath

Menzies Health Institute Queensland

Griffith University QLD 4222

D.Trembath@griffith.edu.au

Tel: 61 7 5678 0103

Abstract

Facilitated Communication (FC) is a non-evidence based intervention with documented dangers that continues to be used with some children with autism spectrum disorders. In this response to Lilienfeld, Marshall, Todd, and Shane (2014), we consider how the findings of our own research involving parents and professionals may contribute to the development of strategies aimed at countering FC and other unsupported practices. We also consider the ways in which misinformation may be contributing to the persistence of FC. Together, we affirm Lilienfeld et al.'s (2014) recommendation that countering FC requires a comprehensive and concerted effort, which must build awareness, capacity, and resilience within parents, professionals, and organizations to adopt only evidence-based interventions.

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder affecting approximately 1 in 68 children (Centers for Disease Control and Prevention, 2014) for which a number of evidence-based and non-evidence based interventions are available (National Autism Center, 2015). These include comprehensive interventions aimed at addressing children's needs across all relevant developmental domains (e.g., social, communication, daily living skills) as well as focused interventions targeting specific areas of need (Odom, Boyd, Hall, & Hume, 2010). There is currently no single best intervention for all children with ASD (Trembath & Vivanti, 2014). Hence, clinicians are advised (e.g., American Speech Language and Hearing Association, 2006; Speech Pathology Australia, 2010) to select from the interventions within an evidence-based practice framework for decision making (Schlosser & Raghavendra, 2004). However, it is also established that there are some interventions that have no empirical evidence of having worked for any children with ASD, of which Facilitated Communication (FC) is arguably the most prevalent and concerning, given the well-established risks and damage it has caused (Boynton, 2012).

The Persistence of Facilitated Communication

Lilienfeld, Marshall, Todd, and Shane (2014) present a compelling account of how FC has continued to impact the lives of individuals with ASD and their families, despite having been scientifically discredited for more than 15 years. In essence, FC involves a 'facilitator' making physical contact with the hand, wrist, arm, or shoulder of a person with disability as he or she selects symbols (letters, words, pictures) on an augmentative and alternative communication (AAC) system or computer keyboard. Symbols selected as part of this process are interpreted by those providing FC to be the person's communication. As Lilienfeld et al. (2014) identified, the results of rigorous scientific studies have consistently demonstrated evidence of inadvertent facilitator control over the person's actions, deeming

this technique ineffective and arguably exploitative. Consequently, the International Society for Augmentative and Alternative Communication (2014, p. 358) has declared that it “does not support FC as a valid form of AAC, a valid means for people to access AAC, or a valid means to communicate important life decisions;” a position consistent with that of a host of national and international organizations. Yet despite these unequivocal statements, Lilienfeld et al. (2014) report that FC continues to be used with individuals with ASD, it persists in some academic and institutional settings, and its use may actually be increasing in popularity due to the sharing of information and advice through social media (Hemsley & Dann, 2014).

Deyro, Simon, and Guay (2014) provided recent evidence for the persistent use of FC in a survey of 83 parents of children with ASD (under 21 years) regarding (a) the interventions they had used with their children, (b) the sources of information they used when selecting interventions, and (c) their perceptions regarding the effectiveness and scientific validity of the interventions they selected. Deyro et al. then compared the parents’ responses to the intervention list and evidence ratings presented in the National Standards Report (National Autism Center, 2009). The NSR featured 11 *established*, 22 *emerging*, and 5 *unestablished* interventions including FC, with the ratings based on the quality, quantity, and consistency of research evidence. Deyro et al. reported that FC was the eighth most commonly used intervention by parents, ranking higher than interventions with *established* evidence ratings including joint attention intervention (rank = 11), naturalistic teaching (rank = 15), and pivotal response training (rank = 17) according to the NSR. While at least half of the parents agreed with the NSR ratings for the majority of *established* interventions, the opposite was true for FC and other *unestablished* interventions. In fact, 66.7% of participants perceived FC to be an *emerging* or *established* intervention, while only 12.7% rated it as *ineffective/harmful*. These findings indicate that not only is FC commonly used, but also that

parents may (a) not be aware of the research evidence and relevant position statements pertaining to its use or (b) choosing and/or being advised to ignore the evidence.

Lilienfeld et al (2014) suggested that the resilience of FC in the face of overwhelming scientific evidence points to the need for an ongoing, multifaceted, and sophisticated approach to countering its popularity. They proposed a range of strategies including (a) "...sustained educational efforts to provide longterm 'immunization' against questionable claims regarding FC and other fad techniques for autism" (p. 29), (b) affirming "...the responsibility of communication disorder and mental health professionals to steadfastly serve as the first line of defence against pseudoscience by thoughtfully and temperately dissuading vulnerable parents from the perils of such practices" (p. 30), and (c) urging "...scientists in the communication disorders, psychological, and educational arenas to become more vocal in their opposition to fad interventions of all kinds" (p. 31). Herein, we consider these recommendations with respect to the findings of our own research examining parents' and professionals' attitudes towards the use of evidence-based interventions, as well as strategies for countering misinformation. Our aim is to shed further light on the reasons why some parents and professionals continue to use FC and to further inform the development of strategies, such as those proposed by Lilienfeld et al (2014) and others (e.g., Chan & Nankervis, 2014; Hemsley & Dann, 2014; Miranda, 2014; Wombles, 2014) aimed at countering the persistent use of FC and other non-evidence based interventions.

Parents' Attitudes towards Evidence-Based Practice

Although parents (and professionals) commonly select interventions that have little or no research evidence, findings from our research indicate that parents are interested in EBP and at all times aim to employ effective interventions. We conducted a series of focus groups with 20 parents in order to explore their expectations, awareness, and experiences in their efforts to access evidence-based speech-language pathology services for their children with

ASD (Auert, Trembath, Arciuli, & Thomas, 2012). The parents expressed support for all three elements of the EBP framework, which involves basing intervention decisions on the (a) the best available evidence from research, (b) evidence from clinical practice, and (c) the preferences and priorities of fully informed clients and caregivers (Dolloghan, 2007).

However, most parents said that their priority was to find speech-language pathologists (SLPs) with clinical experience who could engage their children effectively (i.e., evidence from clinical practice) and who demonstrated effective communication skills (i.e., ability to accommodate caregiver preferences and priorities).

Lina, for example, stated:

“In picking a therapist I want them to be nice. It’s probably my number one criteria. I’ve gotta be happy, yeah, feel comfortable with them.” (p.113)

In contrast, few parents indicated that they explicitly sought SLPs who would provide information about the evidence for the interventions provided, instead expecting that SLPs would use only evidence-based interventions:

... I’m sure there’s like guidelines for those kinds of things ... most people aren’t told what the guidelines are and there’s nowhere to find the guidelines. Because that’s the sort of thing that they would’ve been given probably at university or by their supervisor...” (Rachel, p.114)

Therefore, if a professional is able to engage the child effectively and establish good communication with parents, they may be afforded the parents’ confidence and support, irrespective of whether they are providing an evidenced-based or unsupported intervention. Consequently, we suggest that SLPs and other professionals have a responsibility to provide parents with accurate and timely information about the interventions they provide, even if not asked to do so directly. However, in order for professionals to do so, they must (a) perceive that parents want and need such information and (b) have knowledge of the research

literature.

Professionals' Attitudes towards Parents' need for Information

Recently (Trembath, Hawtree, Arciuli, & Caithness, 2015), we asked 22 SLPs what they thought parents of children with ASD expected of them when it came to the delivery of evidence-based interventions. Using semi-structured interviews and thematic analysis, we found that the SLPs believed that parents wanted to know that the interventions provided to their children are evidence-based, but that a number of factors impact on the nature, amount, and timing of information provided. These factors included the parent's education level, the time since their child's diagnosis, and their prior experiences accessing intervention services. The participants reported that providing information required conscious effort, expertise in communicating with parents, and tailored and timely provision of information. Consistent with Auert et al.'s (2012) earlier findings, the SLPs reported that parents rarely asked for information about the research evidence for interventions provided, instead trusting in their clinical experience and presumed knowledge of the evidence.

The trust that parents invest in professionals to select interventions is further evidenced in Deyro et al.'s (2014) finding that 48% of the 552 parents surveyed rated professionals as the most trusted source of information when it came to selecting treatments for their children. The fact that professionals are a trusted source of information implies a plausible mechanism for increasing the uptake of evidence-based interventions, to the exclusion of FC and other non-evidenced based interventions. However, the quality of information they provide to parents depends on their own knowledge of the research evidence for the interventions they provide. Therefore, to understand the role professionals may play in the continued use of FC, it is important to consider their knowledge and use of FC and other interventions.

Professionals' Knowledge and Use of Evidence-Based Practice

Recently, we examined staff knowledge, attitudes towards, and use of evidence-based practices in a community-based ASD early intervention service (Paynter & Keen, 2015). Ninety-nine professional and paraprofessional staff across metropolitan and regional areas in one state of Australia completed a questionnaire on EBP. The participants reported greater knowledge and use of supported practices (e.g., Naturalistic Teaching Strategies) compared to *emerging* (e.g., Sign Language Instruction) and *unsupported* (e.g., FC) practices, as per the National Standards Report ratings (National Autism Center, 2009). Yet, while the finding appears positive, it is limited by our measure of self-reported, as opposed to observed, knowledge and use of practices. In addition, the participant responses were not uniform. Specifically, knowledge and use of supported practices was higher in metropolitan than in regional locations, and paraprofessionals (e.g., teaching assistants) reported greater use of unsupported practices and lower levels of knowledge and use of supported practices than professionals (e.g., SLPs, occupational therapists, teachers). While it is concerning that unsupported practices were being used by some staff, the findings suggest that there are variables (e.g., training, geographically-based factors impacting on knowledge and use) that are presumably malleable to change.

We found similar results in a follow-up study (Paynter et al., 2015) involving a survey of 72 staff working in four early intervention centres across four states and territories in Australia. Staff self-reported that they use a range of emerging and established interventions, but also FC and other unsupported interventions. We found greater self-reported use of unsupported practices, including FC, amongst paraprofessionals than professionals. These findings are broadly consistent with those of our earlier study (Cheung, Trembath, Arciuli, & Togher, 2013), in which we identified workplace factors (e.g., location, access to resources, organisation culture) can influence knowledge and use of EBP.

Participants also reported that the most frequently reported source of information they access when selecting interventions was within-organisation and external professional development, but participants also rated information from other professionals as ‘very trustworthy.’ Such a finding is concerning given that professional development opportunities in unsupported practices, including FC, are readily available in Australia (e.g., Queensland Facilitated Communication Training Incorporated, 2015), and may help to account for the persistent use of FC reported by participants across the four states.

Factors Impacting on Knowledge and Use of EBP

There are a number of additional explanations for why some professionals continue to use FC and other unsupported interventions. Although reviews of the evidence (e.g., Odom, Collet-Klingenberg, Rogers, & Hatton, 2010; Prior & Roberts, 2012; Wong et al., 2013) for ASD are widely available, this does not necessarily translate into uptake and consideration in decision-making. For example, we found that only about 60% of ASD early intervention staff reported information from treatment reviews (e.g., good practice guidelines) as a source of information accessed or received to inform intervention choices (Paynter et al., 2015). For those who received this information, it was rated as being highly trusted; however, it may be that those with greater trust in research and researchers were more likely to seek out such information.

Trust in science and understanding of the scientific process may influence whether professionals use strategies based on evidence or continue to use FC and other unsupported interventions. It may be, like the general population (e.g., in Australia see Wyatt & Stolper, 2013), that challenges with science literacy exist that preclude understanding of the research process and interpretation of research evidence by at least some professionals. With an abundance of information available of varying quality, it may be that for some professionals, it is difficult to discriminate between levels of evidence (e.g., anecdotes/case studies as used

by FC supporters vs. clinical trials or meta-analyses that may be more challenging to interpret). In addition, scepticism of research and researchers (e.g., by special education teachers in Boardman, Argüelles, Vaughn, Hughes, & Klingner, 2005) may lead to professionals making intervention choices that continue the use of unsupported interventions and value anecdotal over more scientific evidence.

Paradoxically, it also appears that the abundance of information available on ASD can actually lead to poorer decision-making. As discussed by Cook, Cook, and Landrum (2013), people often take mental shortcuts to manage information overload that may lead to poorer choices and may explain the continued use of unsupported interventions. For example, busy professionals, as has been argued for consumers making health care choices (Hibbard & Peters, 2003), may focus on only one facet of the information they receive on interventions (e.g., availability of intervention practice) or not make a decision at all and continue with using a variety of intervention approaches as is common in the community (Hess, Morrier, Heflin, & Ivey, 2008; Paynter & Keen, 2015; Stahmer, Collings, & Palinkas, 2005).

Another factor to consider in choice of intervention is the emphasis that professionals place on parent values and preferences. A family-centered approach that takes account of parent values, preferences, and priorities is considered integral to delivering high quality early intervention (Dolloghan, 2007). This may at times lead to tensions between parents and professionals around the use of unsupported interventions, valued or preferred by one of the parties. There is some evidence that parents tend to invest in a range of interventions, some of which may be unsupported (e.g., Call, Delfs, Reavis, & Mevers, 2015; Green et al., 2006). Professionals may feel under pressure to use these interventions in order to honor parental preferences but should, in our opinion, give equal consideration to the research evidence and their obligations under professional codes of ethics and clinical guidelines.

Thus, although professionals appear to be generally supportive of EBP as a concept (Aarons, 2004; Stahmer & Aarons, 2009), the sources of information accessed, skills to interpret and handle information, and parental preferences may lead to use of FC and other unsupported interventions. The results of our studies examining both parents and professionals suggest that more needs to be done to support selection and use of evidence-based interventions, consistent with Lilienfeld et al's recommendation. But how can this be achieved? Efforts to date have focused on giving parents and professionals scientific information and training and resources to critically appraise evidence. As Hemsley and Dann (2014) identified, social media has enormous potential for both disseminating information and engaging parents and professionals in dialogue aimed at promoting EBP. However, as discussed by Lilienfeld et al. and others, tackling FC must involve a multifaceted process, and not just deal with the provision of accurate information, but also deal with the challenge of countering misinformation.

Health Misinformation: Where Does it Come From, Why is it Important, Why do People Believe it?

Health misinformation is by no means restricted to FC and other unsupported ASD interventions and comes from many sources. The internet and “infotainment” media channels naturally provide a wide range of helpful, but also misleading or at least questionable, health content (Kata, 2010; Purcell, Wilson, & Delamothe, 2002). Health and lifestyle bloggers may use misinformation to promote themselves and their cause (Freeman, 2015) or a sponsored product (Lu, Chang, & Chang, 2014). Vested interests spread misinformation to secure profits (Barrett & Herbert, 1994; Oreskes & Conway, 2010; Proctor, 2011). Health myths are kept alive through social media (Scanfeld, Scanfeld, & Larson, 2010) or through the modern media's tendency to always look at both sides of a story, even when the weight of available evidence lies firmly on one side only (Clarke, 2008).

Misinformation can have severe negative implications, and this is particularly true of health misinformation. Unwarranted belief in treatments that do not work can be just as catastrophic as non-belief in treatments that do work. Examples include false belief in the effectiveness of herbal and food remedies to treat HIV/AIDS (Chigwedere, Seage, Gruskin, Lee, & Essex, 2008; Kalichman, 2014), as well as denial of the effectiveness and safety of childhood vaccinations (Poland & Jacobson, 2001; Rosenau, 2012). As Lilienfeld et al (2014) and others have summarized, belief in FC has led to numerous documented negative health and welfare outcomes for individuals, their families, and professionals involved.

It is somewhat ironic that misinformation appears to be a growing problem, even though factual information is more readily available than ever. So why do people rely on misinformation in their reasoning and decision making? To answer this question, we need to think not only about people's motivations, but also about their cognition, and how motivation and cognition interact.

It is a truism that people have a strong desire to understand the world around them, in particular when they are confronted by challenging situations. For parents of children with ASD who use little or no speech, trying to understand how much their children understand, why they are not talking, and wondering whether they will learn to talk or communicate via other means, is such an example. In this circumstance, the absence of a satisfactory explanation that is both plausible and simple opens the door for misinformation. People prefer simple over more-complex explanations (Chater & Vitanyi, 2003; Lombrozo, 2007), and thus a simple myth may be more attractive than a complicated truth that comes with some uncertainty. Unfortunately, the possible explanations for why children with ASD may not be talking, like many explanations in the health and medical field, are multi-factorial and probabilistic rather than simple and straightforward, as they must account for the pervasive impairments across multiple developmental domains, as well as a range of personal (e.g.,

biological and behavioral characteristics) and environmental (e.g., exposure to interventions) factors. In fact, just as there is no single known cause for ASD, there is no single and simple explanation for why many children with ASD struggle to develop an effective, spontaneous, flexible, directed, and independent mode of communication.

Moreover, while there is unprecedented access to information, this does not necessarily mean good access to *high-quality* information: there are both financial (e.g., pay-walls) and cognitive (e.g., unintelligible terminology) obstacles to knowledge access. As noted above, even when information is accessible, people have processing limitations in terms of available time, cognitive resources, or motivation, and thus it is not always possible to thoroughly assess all the available evidence when forming a belief or making a decision. In these situations, people often turn to heuristics—mental rules of thumb that facilitate quick assessments with limited effort (cf. Gigerenzer & Gaissmaier, 2011). For example, when encountering a new piece of information, people may ask “Have I heard this before?” or “How does this fit in with what I already know?” By-and-large, such heuristics work well, but they can lead to biases such as the confirmation bias, where information is selected or interpreted in a way that confirms existing beliefs (Nickerson, 1998). Thus, when one’s existing knowledge or belief is incorrect, the use of heuristics will serve to strengthen them further. In sum, people rely on misinformation when it provides simple, plausible, and easily accessible explanations that correspond with their existing views of the world.

How to Correct Health Misinformation

In light of this, how can misinformation be corrected? Lilienfeld et al (2014, p.31) made the astute observation that “Scientists who wish to counteract the persistence of FC and other questionable methods, such as recovered memory techniques, must also acquaint themselves with the growing corpus of research on effective and ineffective methods of dispelling misconceptions.” An information-deficit view of knowledge communication

(Blake, 1999) assumes that simply providing people with factual information is sufficient to avoid reliance on misinformation. However, this simplistic view largely ignores the above-mentioned factors of simplicity, plausibility, and worldview, which need to be taken into account when debunking myths (for a review, see Lewandowsky, Ecker, Seifert, Schwarz, & Cook, 2012). Six key points are worth noting as outlined below.

First, mere retractions of misinformation are surprisingly ineffective. Even in the absence of any motivation to believe one version or the other, a plain “this information has been shown to be incorrect” statement will at most halve the reliance on the retracted information in people’s subsequent reasoning, even when people demonstrably understand and remember the retraction (Ecker, Lewandowsky, Swire, & Chang, 2011; Ecker, Lewandowsky, & Tang, 2010). This effect is known in the psychological literature as the continued influence effect of misinformation (Johnson & Seifert, 1994; Seifert, 2002). Mental model theory (Bower & Morrow, 1990) can be applied to illustrate this effect: It is assumed that as people accumulate information about an event or a set of circumstances, they build a mental model of the world, and they want this model to be complete. A retraction creates a gap in such a mental model, and leaves a person in a state of cognitive conflict—having information available in memory that “completes” the model but also knowing it has been retracted. When prompted by questions, the retracted information may thus still be used if no alternative information is available. Therefore, simply saying “FC does not work” will be insufficient to alter beliefs and behaviors.

Second, it follows that the provision of a fact-based alternative account is crucial because it can fill the model gap created by the retraction (Ecker et al., 2010; Johnson & Seifert, 1994; Seifert, 2002). However, as alluded to earlier, the alternative information will compete with the misinformation in memory (cf. Ayers & Reder, 1998) and thus the facts need to be communicated in a way that makes them easy to understand and as plausible as the

misinformation. Fortunately, a variety of resources are available to help parents and professionals learn about the current range evidence-based interventions (e.g., research reviews, parent-friendly research summaries, free online professional development modules), thus allowing for a tailored approach to providing this information.

Third, when retracting misinformation, science communicators and health professionals are well-advised to focus on the facts and avoid unnecessary repetition of misinformation. This is because repetition makes misinformation more familiar, and people believe and trust familiar things. In extreme cases, myth retractions that repeat the myth can ironically increase the false beliefs they aim to reduce (Schwarz, Sanna, Skurnik, & Yoon, 2007). Corrections should always start with and emphasize the facts, and if a myth needs to be repeated, it should be prefaced by a warning that what is about to follow is misinformation (e.g., “Attention, myth follows...”) to put recipients into a more careful mode of processing (Ecker et al., 2010). The misinformation should then be followed by a detailed refutation (Kowalski & Taylor, 2009). Such an approach is particularly relevant to ‘immunizing’ parents whose children have recently been diagnosed and future health and education professionals, who may not have yet been exposed to information about FC and other unsupported practices.

Fourth, if people hold strong attitudes and beliefs, they will readily accept familiar, attitude-congruent misinformation, and they will defend their beliefs by counterarguing “inconvenient” retractions (Prasad et al., 2009). Again, in extreme cases, corrections that are incongruent with a person’s beliefs can ironically strengthen the very misconceptions they set out to correct (Nyhan & Reifler, 2010)—in other words, worldview-dissonant corrections can backfire and cause stronger misbelief. It is therefore important to consider a person’s worldview when formulating a correction. For example, corrective information can be framed in a way that takes the recipient’s worldviews into account (e.g., conservatives are more open

to climate science information when business opportunities are emphasized rather than government intervention; Kahan, 2010). In the case of FC, parents and professionals are more likely to be open to information about adopting evidence-based alternatives to FC if they are assured that the alternative interventions will support the children's right to communicate (i.e., congruent with their values and beliefs).

Fifth, if possible, myth corrections should utilize well-designed graphs. Graphical presentation of data can be easier to process than complex verbal descriptions. Furthermore, the quantitative specification of true effects and trends can make it more difficult to argue against attitude-incongruent retractions (Lewandowsky, 2011; Nyhan & Reifler, 2011).

Finally, it is known that source credibility plays a significant role in persuasion, and source trustworthiness in particular is an important factor in belief formation (cf. Pornpitakpan, 2004). If possible, corrections of misinformation should thus come from a trusted source. Our research indicates that parents trust early intervention providers (Auert et al., 2012; Trembath et al., 2015) and professionals trust other professionals (Paynter et al., 2015), meaning that both groups are already engaging in trusting relationships that can be leveraged to disseminate information about evidence-based interventions. Research suggests that when retracting misinformation, source trustworthiness is even more important than the retraction source's perceived expertise (Guillory & Geraci, 2013).

Misinformation and Ongoing Reliance on Ineffective Treatments

As discussed earlier, misinformation is particularly difficult to correct if it comes from a trusted source, and is plausible, easy-to-understand, familiar, and in line with existing beliefs or other motivations. All these factors will play a role in the continued belief in and reliance on non-evidence-based interventions such as FC. Misinformation regarding the effectiveness of these "treatments" may come from a well-meaning friend, a trusted blog, or an organization with a scientific-sounding name. To a layperson, the rationale behind the

treatments may be perfectly plausible and—as with most myths—easy to comprehend. Information on these treatments will evoke highly familiar notions such as the idea that a person is fully literate and cognitively able, but ‘trapped’ in his or her own body without an effective communication mode. Arguably the most important aspect, however, is that the treatment’s rationale will correspond and resonate with parents’ attitudes, hopes, and beliefs.

There is no doubt that parents of children with developmental disorders have a strong motivation to help their children, combined with a willingness to trust professionals with experience who build rapport with their children effectively and have good communication skills (Auert et al., 2012). More fundamentally, a view that significant communication disability in children with ASD is the result of a difficulty with motor planning is inherently less unsettling than the idea of a more pervasive impairment in cognition. In the case of FC, the rhetoric utilized in its promotion goes even further, insinuating that alternative treatment perspectives deny patients the fundamental human right of communication (and subtly instilling guilt in parents who dismiss the treatment). After all, who would argue with the notion that “everyone has something to say and a right to say it” (Autism National Committee, 2008)? Thus, belief in the misinformation that FC is a helpful therapeutic tool (which is incorrect) will to a certain extent be driven by a belief that the child or adult in question is a fully-fledged member of society who has the same rights as any other person (which is true, or which at least is a point most people would agree with). This makes it particularly difficult to correct the misinformation: the incorrect misinformation needs to be de-coupled from the correct underlying supportive beliefs.

Summary and Conclusion

The use of FC with children with ASD persists despite overwhelming evidence against its use from multiple well-designed research studies and the demonstrated risks for those involved. This persistence is likely due to a multitude of factors, including parental

knowledge, professional knowledge and practices, and the challenges associated with countering misinformation in the digital age. It is important to note that the challenges associated with FC are not unique to the field of ASD, just as the challenges associated with misinformation exist across every aspect of society. Thus, strategies that have been, or will be, developed as part of the broader scientific community to counter misinformation on other issues (e.g., climate change, vaccinations) may well be effectively applied in response to FC.

There is clear evidence that parents want effective treatments for their children with ASD and that they often trust professionals to select evidence-based interventions. As Lilienfeld et al. (2014) noted, professionals have a key role to play in ‘immunising’ parents against unsupported interventions, and advocating for evidence-based alternatives. The findings of our research indicate that the majority of professionals adopt evidence-based interventions, but not all, and not all of the time. Factors that appear to impact on intervention selection, including the professionals’ training, knowledge, and access to appropriate resources, as well as their desire to incorporate caregivers’ preferences and priorities with the EBP framework. These factors represent plausible targets for parent and professional focused interventions aimed at countering the use of unsupported practices.

Misinformation is powerful and efforts to counter FC and other unsupported practices should draw on the lessons learned from the substantial body of research in the area. In summary, when correcting myths about FC and other unsupported interventions, health professionals should first endeavour to build trusting relationships. Our research suggests that most professionals are committed to forming effective clinician-client relationships. Second, professionals should give parents the facts and the evidence, both for effective, and against ineffective, treatment options. This requires knowledge of the research evidence, which in many cases means ensuring professionals have access to the many excellent resources already available rather than creating additional resources. Within organizations, it is paramount that

effective models of EBP translation and utilization are developed to build knowledge, resilience, and leadership within the staff community to ensure only evidence-based interventions are used. Fortunately, the research findings into FC are clear and consistent over time, so professionals do not have the added challenge of dealing with an evolving evidence-base. Third, professionals need to explain effective treatment options in simple language, potentially with the use of figures and graphs to make the information accessible. Finally, in proposing evidence-based interventions aimed at addressing the complex issue of how best to support minimally verbal children with ASD to communicate, professionals need to affirm parents in their belief that their children do indeed have something to say and a right to say it—only, they should say it themselves.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Acknowledgements

David Trembath is funded by the National Health and Medical Research Council [GNT1071811].

References

- Aarons, G. A. (2004). Mental health provider attitudes towards adoption of evidence-based practice: The evidence-based practice attitude scale (EBPAS). *Mental Health Services Research, 6*, 61-74.
- American Speech Language and Hearing Association. (2006). Guidelines for Speech-Language Pathologists in Diagnosis, Assessment, and Treatment of Autism Spectrum Disorders Across the Life Span Retrieved 01/04/11, from <http://www.asha.org/docs/html/gl2006-00049.html>
- Auert, E. J., Trembath, D., Arciuli, J., & Thomas, D. (2012). Parents' expectations, awareness, and experiences of accessing evidence-based speech-language pathology services for their children with autism. *International Journal of Speech-Language Pathology, 14*, 109-118.
- Autism National Committee (2008). *Autism National Committee (AutCom) policy and principles regarding facilitated communication*. Available from <http://www.autcom.org/articles/PPFC.pdf>
- Ayers, M. S., & Reder, L. M. (1998). A theoretical review of the misinformation effect: Predictions from an activation-based memory model. *Psychonomic Bulletin & Review, 5*, 1-21.
- Barrett, S., & Herbert, V. (1994). *The vitamin pushers: How the health food industry is selling America a bill of goods*. Amherst, NY: Prometheus Books.
- Blake, J. (1999). Overcoming the 'value-action gap' in environmental policy: Tensions between national policy and local experience. *Local Environment, 4*, 257-278.
- Boardman, A. G., Argüelles, M. E., Vaughn, S., Hughes, M. T., & Klingner, J. (2005). Special education teachers' views of research-based practices. *The Journal of Special Education, 39*, 168-180.

- Bower, G. H., & Morrow, D. G. (1990). Mental models in narrative comprehension. *Science*, 247, 44-48.
- Boynton, J. (2012). Facilitated Communication—what harm it can do: Confessions of a former facilitator. *Evidence-Based Communication Assessment and Intervention*, 6, 3-13.
- Call, N. A., Delfs, C. H., Reavis, A. R., & Mevers, J. L. (2015). Factors influencing treatment decisions by parents for their children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 15–16, 10-20.
- Centers for Disease Control and Prevention. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010 *Surveillance Summaries* (Vol. 63(SS02), pp. 1-21).
- Chan, J., & Nankervis, K. (2014). Stolen voices: Facilitated communication is an abuse of human rights. *Evidence-Based Communication Assessment and Intervention*, 8, 151-156. doi: 10.1080/17489539.2014.1001549
- Chater, N., & Vitanyi, P. (2003). Simplicity: A unifying principle in cognitive science. *Trends in Cognitive Science*, 7, 19-22.
- Cheung, G., Trembath, D., Arciuli, J., & Togher, L. (2013). The impact of workplace factors on evidence-based speech-language pathology practice for children with autism spectrum disorders. *International Journal of Speech-Language Pathology*, 15, 396-406.
- Chigwedere, P., Seage, I., G. R., Gruskin, S., Lee, T.-H., & Essex, M. (2008). Estimating the lost benefits of antiretroviral drug use in South Africa. *Journal of Acquired Immune Deficiency Syndrome*, 49, 410-415.

- Clarke, C. (2008). A question of balance: The autism-vaccine controversy in the British and American elite press. *Science Communication, 30*, 77-107.
- Cook, B. G., Cook, L., & Landrum, T. J. (2013). Moving research into practice: can we make dissemination stick? *Exceptional Children, 79*, 163-180.
- Deyro, M. C., Simon, E. W., & Guay, J. (2014). Parental awareness of empirically established treatments for autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*. Advance online publication. doi: 10.1177/1088357614559210
- Dolloghan, C. (2007). *The handbook for evidence-based practice in communication disorders*. University of Michigan: Paul H. Brookes.
- Ecker, U. K. H., Lewandowsky, S., Swire, B., & Chang, D. (2011). Correcting false information in memory: Manipulating the strength of misinformation encoding and its retraction. *Psychonomic Bulletin & Review, 18*, 570-578.
- Ecker, U. K. H., Lewandowsky, S., & Tang, D. T. W. (2010). Explicit warnings reduce but do not eliminate the continued influence of misinformation. *Memory & Cognition, 38*, 1087-1100.
- Freeman, H. (2015). Pseudoscience and strawberries: 'Wellness' gurus should carry a health warning. *The Guardian*, April, 23, 2015. Available from <http://www.theguardian.com/commentisfree/2015/apr/22/wellness-gurus-belle-gibson-pseudoscience>
- Gigerenzer, G., & Gaissmaier, W. (2011). Heuristic decision making. *Annual Review of Psychology, 62*, 451-482.
- Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities, 27*, 70-84.

- Guillory, J. J., & Geraci, L., (2013). Correcting erroneous inferences in memory: The role of source credibility. *Journal of Applied Research in Memory and Cognition, 2*, 201-209.
- Hemsley, B., & Dann, S. (2014). Social media and social marketing in relation to facilitated communication: Harnessing the affordances of social media for knowledge translation. *Evidence-Based Communication Assessment and Intervention, 8*, 187-206.
- Hess, K. L., Morrier, M. I. J., Heflin, L. J., & Ivey, M. L. (2008). Autism treatment survey: services received by children with autism spectrum disorders in public school classrooms. *Journal of Autism and Developmental Disorders, 38*, 961-971.
- Hibbard, J. H., & Peters, E. (2003). Supporting informed consumer health care decisions: Data presentation approaches that facilitate the use of information in choice. *Annual Review of Public Health, 24*, 413-433.
- International Society for Augmentative and Alternative Communication. (2014). ISAAC Position Statement on Facilitated Communication. *Augmentative and Alternative Communication, 30*, 357-358.
- Johnson, H. M., & Seifert, C. M. (1994). Sources of the continued influence effect: When misinformation in memory affects later inferences. *Journal of Experimental Psychology: Learning, Memory, and Cognition, 20*, 1420-1436.
- Kahan, D. M. (2010). Fixing the communications failure. *Nature, 463*, 296-297.
- Kalichman, S. C. (2014). The psychology of AIDS denialism: Pseudoscience, conspiracy thinking, and medical mistrust. *European Psychologist, 19*, 13-22.
- Kata, A. (2010). A postmodern Pandora's box: Anti-vaccination misinformation on the internet. *Vaccine, 28*, 1709-1716.
- Kowalski, P., & Taylor, A. K. (2009). The effect of refuting misconceptions in the introductory psychology class. *Teaching of Psychology, 36*, 153-159.

Lewandowsky, S. (2011). Popular consensus: Climate change is set to continue.

Psychological Science, 22, 460-463.

Lewandowsky, S., Ecker, U. K. H., Seifert, C. M., Schwarz, N., & Cook, J. (2012).

Misinformation and its correction: Continued influence and successful debiasing.

Psychological Science in the Public Interest, 13, 106-131.

Lilienfeld, S. O., Marshall, J., Todd, J. T., & Shane, H. C. (2014). The persistence of fad interventions in the face of negative scientific evidence: Facilitated communication for autism as a case example. *Evidence-Based Communication Assessment and Intervention*, 8, 62-101.

Lombrozo, T. (2007). Simplicity and probability in causal explanation. *Cognitive Psychology*, 55, 232-257.

Lu, L.-C., Chang, W.-P., & Chang, H.-H. (2014). Consumer attitudes toward blogger's sponsored recommendations and purchase intention: The effect of sponsorship type, product type, and brand awareness. *Computers in Human Behavior*, 34, 258-266.

Miranda, P. (2014). Comments and a personal reflection on the persistence of facilitated communication. *Evidence-Based Communication Assessment and Intervention*, 8, 102-110.

National Autism Center. (2009). National Standards Report: Addressing the need for evidencebased practice guidelines for autism spectrum disorders. Randolph, MA: National Autism Center.

National Autism Center. (2015). National Standards Report. Randolph, MA: National Autism Center.

Nickerson, R. S. (1998). Confirmation bias: A ubiquitous phenomenon in many guises. *Review of General Psychology*, 2, 175-220.

- Nyhan, B., & Reifler, J. (2011). *Opening the political mind? The effects of self-affirmation and graphical information on factual misperceptions*. Unpublished manuscript, Dartmouth College.
- Odom, S. L., Boyd, B. A., Hall, L. J., & Hume, K. (2010). Evaluation of comprehensive treatment models for individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 40*, 425-436.
- Odom, S. L., Collet-Klingenberg, L., Rogers, S. J., & Hatton, D. D. (2010). Evidence-based practices in interventions for children and youth with autism spectrum disorders. *Preventing School Failure: Alternative Education for Children and Youth, 54*, 275-282.
- Oreskes, N., & Conway, E. M. (2011). *Merchants of doubt: How a handful of scientists obscured the truth on issues from tobacco smoke to global warming*. Bloomsbury Publishing USA.
- Paynter, J., Ferguson, S., Fordyce, K., Joosten, A., Paku, S., Stephens, M., . . . Keen, D. (2015). *Implementation of evidence-based practices by ASD early intervention service providers: Translating research to practice*. (Unpublished Manuscript).
- Paynter, J., & Keen, D. (2015). Knowledge and use of intervention practices by community-based early intervention service providers. *Journal of Autism and Developmental Disorders, 45*, 1614-1623.
- Poland, G. A., & Jacobson, R. M. (2001). Understanding those who do not understand: A brief review of the anti-vaccine movement. *Vaccine, 19*, 2440-2445.
- Pornpitakpan, C. (2004). The persuasiveness of source credibility: A critical review of five decades' evidence. *Journal of Applied Social Psychology, 34*, 243-281.

Prasad, M., Perrin, A. J., Bezila, K., Hoffman, S. G., Kindleberger, K., Manturuk, K., . . .

Powers, A. S. (2009). "There must be a reason": Osama, Saddam, and inferred justification. *Sociological Inquiry*, 79, 142–162.

Prior, M., & Roberts, J. (2012). Early Intervention for Children with Autism Spectrum

Disorders: 'Guidelines for Good Practice'. Retrieved from

http://www.fahcsia.gov.au/sites/default/files/documents/11_2012/early_intervention_practice_guidelines.pdf

Proctor, R. N. (2011). *Golden holocaust: origins of the cigarette catastrophe and the case for abolition*. Berkeley, CA: University of California Press.

Purcell, G. P., Wilson, P., & Delamothe, T. (2002). The quality of health information on the internet: As for any other medium it varies widely; regulation is not the answer.

British Medical Journal, 324, 557-558.

Queensland Facilitated Communication Training Incorporated. (2015). Welcome to QLD

Facilitated Communication Training Inc. Retrieved 18/06/15, from

<http://www.qldfctinc.com.au/>

Rosenau, J. (2012). Science denial: A guide for scientists. *Trends in Microbiology*, 20 , 567-569.

Scafield, D., Scafield, V., & Larson, E. L. (2010). Dissemination of health information

through social networks: Twitter and antibiotics. *American Journal of Infection Control*, 38, 182-188.

Schlosser, R. W., & Raghavendra, P. (2004). Evidence-based practice in augmentative and alternative communication. *Augmentative and Alternative Communication*, 20, 1-21.

Schwarz, N., Sanna, L. J., Skurnik, I., & Yoon, C. (2007). Metacognitive experiences and the intricacies of setting people straight: Implications for debiasing and public

information campaigns. *Advances in Experimental Social Psychology*, 39, 127-161.

- Seifert, C. M. (2002). The continued influence of misinformation in memory: What makes a correction effective? *The Psychology of Learning and Motivation, 41*, 265-292.
- Speech Pathology Australia. (2010). *Position Paper: Evidence based speech pathology practice for individuals with autism spectrum disorder*. Melbourne: Speech Pathology Australia.
- Stahmer, A. C., & Aarons, G. (2009). Attitudes toward adoption of evidence-based practices: A comparison of autism early intervention providers and children's mental health providers. *Psychological Services, 6*, 223-234.
- Stahmer, A. C., Collings, N. M., & Palinkas, L. A. (2005). Early intervention practices for children with autism: descriptions from community providers. *Focus on Autism and Other Developmental Disabilities, 20*, 66-79.
- Trembath, D., Hawtree, R., Arciuli, J., & Caithness, T. (2015). *What do speech pathologists think parents expect when treating their children with ASD?* Paper presented at the Speech Pathology Australia National Conference, Canberra, Australia.
- Trembath, D., & Vivanti, G. (2014). Problematic but predictive: individual differences in children with autism spectrum disorders. *Int J Speech Lang Pathol, 1*, 57-60.
- Wombles, K. (2014). Some fads never die—they only hide behind other names: Facilitated communication is not and never will be augmentative and alternative communication. *Evidence-Based Communication Assessment and Intervention, 8*, 181-186.
- Wong, C., Odom, S. L., Hume, K., Cox, A. W., Fettig, A., Kucharczyk, S., . . . Schultz, T. R. (Eds.). (2013). *Evidence-Based Practices for Children, Youth, and Young Adults With Autism Spectrum Disorder*. Chapel Hill: The University of North Carolina: Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.

Wyatt, N., & Stolper, D. (2013). Science literacy in Australia. Retrieved from <https://21-science.cdn.aspedia.net/sites/default/files/user-content/resources/file/scienceliteracyreport.pdf>