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Submission by FCT Qld Inc to the Senate Inquiry on Prevalence of different types of speech, language and communication disorders and speech pathology services in Australia.

Attached is a submission to the Senate Inquiry into the need for, availability and adequacy of speech pathology services in Australia.

I am pleased to make this submission on behalf of FCT Qld Inc a community based organisation incorporated under the Queensland legislation. The association was formed to promote best practice of Facilitated Communication in Queensland and to foster quality training and delivery of this Augmentative and Assistive Communication strategy.

This submission has been endorsed by the executive of FCT Qld Inc.

Should the Inquiry require further explanation or clarification of matters contained in our submission I can be contacted by phone on 07 3396 6604 or by post to 691 The Esplanade, Lota, Brisbane, Queensland 4179, or email at bill.kingston@optusnet.com.au.

I would appreciate advice regarding any public hearings to be held in Brisbane and would, of course, make myself available if the committee required any direct response.

BILL KINGSTON
President
FCT Qld Inc
21 February 2014

INTRODUCTORY STATEMENT

The Terms of Reference for this Inquiry seek advice in part on:

- c. the availability and adequacy of speech pathology services provided by the Commonwealth, state and local governments across health, aged care, education, disability and correctional services; and
- d. the provision and adequacy of private speech pathology services in Australia
- e. evidence of the social and economic cost of failing to treat communication and swallowing disorders

I am not aware of any recent reliable data on these questions in Australia but would refer to the following references cited by Jane Remington-Gurney MA.LCST in an introductory Manual to Facilitated Communication Training:

- 34% of children with language disorders also have behavioural problems (Willinger, U., Brunner, E., Diendorfer-Radner, G., Sams, J., Sirch, U., & Eisenwort, B. 2003).
- Between 60 and 70% of young offenders [adolescents] have an undiagnosed Language Disorder, linked with under achieving (*Snow, P. & Powell, M. 2004*)
- 20% of parents report that their child has a communication impairment and 20.8% of 4-5 year olds were reported by teachers to have expressive language disorders (*McLeod, S. & Harrison, L. 2006*)
- 41-75% of children with early language disorders continue to show reading problems at the age of 8 years. (*McLeod, S & Harrison, L. 2006*)
- One in one hundred [1:100] children are affected by autism in Australia. (*Autism Australia May 2002*).
- A conservative estimate of the number of people with severe communication impairments [who need the assistance of another person to effect communication] is 1-2% of the population. (www.Scotland.gov.uk/publications/2007/06/12121646/4 *Communication Support Needs: A review of the literature*)

While many of these citations are of some age I would suggest that they are indicative of an ongoing need and, with respect to the Scottish data I would ask if anyone can provide reasons that the situation would vary greatly in Australia.

With respect to supply and provision of Speech Pathology services I can only say that, as I suspect would be the case in other states, the further from the metropolitan area the harder it is to find services.

If the statistics cited above are accepted as still being of relevance to Australia there is a demonstrable demand for services and it would be, and is, unacceptable for a proportion of those in need to be denied access to a form of Augmentative and Assistive Communication (AAC) that works for them.

One of the possible limitations on the availability of services for people with CCNs is the limited training available for disability workers, for parents and other carers and, most importantly of all for Speech Pathologists. It is a human characteristic to be resistant to things that we don't understand.

Speech Pathology Australia has recognised this as an issue in its Augmentative and Assistive Communication Clinical Guideline [2012]. SPA also recognises the need for training of all partners engaged in the consideration and implementation of AAC strategies. Their guideline identifies as a principle the need for a multi-professional collaborative approach to foster optimal service delivery.

So far as my organisation is aware there is very limited training on AACs included in Speech Pathology degree courses and, given the rapid evolution of technology based interventions there may be an issue with university teacher awareness of current developments.

Competency based courses have been developed in Australia. If supported and /or mandated for people engaged in the delivery of AAC strategies this would go a long way to ensuring consistency and credibility in delivery in AAC. Key stakeholders for such training include the person with the CCN needs; collaborative partner professionals; family members or guardians and significant others.

My Association and I are very concerned that many potential providers of AAC strategies, and particularly of Facilitated Communication Training [FCT] have been and are being deterred from providing services by a concerted campaign to discredit and disallow potential users to access this form of AAC.

This submission will attempt to explain the heat of the debate that has raged over FCT since the mid – 1990s and demonstrate the flawed evidence upon which much of that heat has been generated.

Schism is a strong word that is used to describe situations where very strong views on a particular issue are taken by opposing camps and seem incapable of resolution. We are all aware of the partisan positions of people taken in relation to religious matters – between Islamic people and followers of Christianity in sub-Saharan Africa; within faiths as exemplified by splits between Sunni and Shiite followers of Mohammed; between Protestants and Catholics in divided countries like Ireland; within the world of science on the divisive issue of evolution as against intelligent design or on the question of climate change between those who believe that human activity is causing global warming and those who believe it is attributable to cyclic patterns of nature.

By the very nature of debate, individuals who have strongly identified with opposing positions will find it difficult to provide unbiased advice to any inquiry or review. As noted by renowned twentieth century philosopher of science, Thomas Kuhn:

“When paradigms enter, as they must, into a debate about paradigm choice, their role is necessarily circular. Each group uses its own paradigm to argue in that paradigm's defence. ... [T]he circular argument ... can not be made logical or even probabilistically compelling for those who refuse to step into the circle. The premises and values shared by the two parties to a debate over paradigms are not sufficiently extensive for that.” (Kuhn, 1962, p94.)

Kuhn adds that revolutions could only be resolved: ... *by men so young or so new to the crisis-ridden field that practice has committed them less deeply than most of their contemporaries to the world view and rules determined by the old paradigm* (Kuhn, 1962, p144)

Among the strategies applied by speech pathologists there is a group of strategies designed to assist people who have Complex Communication Needs [CCN] to engage in communication. These are collectively referred to as Augmentative and Assistive Communication [AAC] strategies.

AAC strategies can include sign language, choice selection from a range of pictures or symbols, and use of assistive technologies such as communication boards, keyboards and high tech devices with speech output. Many people with CCN communicate use a combination of these AAC strategies.

Central to many AAC strategies is the selection of a picture, symbol, letter, or word that is the choice of the person seeking to communicate and that the selection is made by the most appropriate means available to the person wishing to communicate.

For some people with complex physical and or neurological issues that selection requires some assistance and this is where the practice known as Facilitated Communication Training comes into play.

FCT has been at the centre of a schism of sorts between researchers who accept the research methods developed in the mid-1990s and who believe it has no credence and those who are open to further investigations and who accept changes to established research standards.

Deniers of FCT attribute the words keyed by users as being authored by the facilitators involved and wherever evidence arises that contradicts their position it is either ignored or attributed to 'confounding factors'. They reject research that increasingly shows that many members of the cohorts that often use FCT have movement disorders that result in their inability to produce meaningful speech.

Supporters of FCT see it as a credible AAC strategy, especially where there is a strong emphasis on skilled assessment of candidates for its use and a requirement rigorous training of people to deliver the strategy. They note changes to scientific orthodoxy that places greater stress on a cross therapy approach that recognises clinical experience of practitioners and values input from family and the personal preferences of the person whose needs are being considered.

Most of all members of our association see the benefits of FCT nearly every day of their life. Giving non-verbal people the capability to initiate and respond to communication is not only a matter of human rights, it also can prove to be a very effective response to challenging behaviours and a means to personal expression never before experienced by the individual user.

FCT Qld Inc is an incorporated Association of key stakeholders from a range of backgrounds that is committed to providing best practice, information and networking to people who require physical support as an accommodation to movement difference and diversity because “Not being able to speak does not mean that you have nothing to say”.

FCT is a strategy where physical support is provided to steady but not direct movement to units of meaning on a communication array. Units of meaning can be drawings, symbols, photos, words or individual letters. With trained communication facilitators and much practice many users of this strategy develop the capability to use pointing movements with little or no physical support from a facilitator.

FCT is a strategy that may be able to assist some people with CCN issues but cannot assist all such people.

FCT is not a therapy or treatment for any particular illness or disability; FCT is an access strategy that follows from a careful assessment by a suitably trained and qualified person.

In many instances FCT is one of a number of communication strategies used. This can involve independent access to an iPad or Android device or simple switch devices to confirm or negate a keyed message or request.

Facilitators require quality training in the environmental, physical and interactional supports that make up FC. Importantly, they also require a full awareness of procedures and processes to be implemented where issues of a contentious nature are raised by a user.

FCT emerged in the last quarter of the twentieth century and was received enthusiastically especially in the USA where for a period of time there were no standards applied to determine how candidates were to be assessed or what specific skills facilitators needed to ensure effective communication. Indeed people were assured that anyone could ‘do it’ with little or no training and so the misuse of FC spread almost like wildfire.

This lack of any standards lead to a number of contentious statements attributed to FC users that were challenged and refuted in the legal system and through the media a significant proportion of which subsequently took strongly negative positions on the practice.

A group of researchers, notably from the academic discipline known as Behavioural Psychology designed tests to attempt to confirm the authorship of statements attributed to FC users. A common theme of these tests was that they involved the application of testing user’s abilities in to pass messages. These tests were hailed as providing “Evidence Based” proof that the responses to test questions were commonly authored by the facilitators not by the users. In the few instances where candidates successfully passed messages these results were attributed to undescribed ‘confounding factors’ and dismissed.

When researchers replicated these methods with variable scientific rigour and achieved the same results this became the orthodox response to FCT. Their position was taken to be correct as it was ‘evidence based’ on controlled testing.

Having identified a process that proved their position many researchers took [and have stood by] a position that “when it’s over it’s over”.

There followed a period beginning in the mid-1990s and running through into this century where the information on FCT was ‘updated’ by peer reviews of the previous findings and by further reviews of the reviews. Few, if any researchers looked at the original research design or the detailed results, accepting that the earlier work met scientific standards.

Had such an analysis been undertaken notice might have been taken of the absence of randomly controlled trials; the lack of homogeneity of the test groups in terms age or nature of the diagnoses of the users [rendering the possibility of randomly selected control groups impossible], the stressful situations that candidates were placed in and the dismissal of their pleas and obvious signs of anxiety and discomfort let alone that dismissal of any successful results.

The testing process could be assured to gain the same result and because no-one seriously asked whether the process was a valid test the issue was considered by the mainstream as being settled once and for all.

By the start of the twenty-first century questions were being raised about the validity of the orthodox position. The problem was [and for many still is] that many of the references to authority by opponents of FCT rely upon reviews of the original research but do not test or question the validity of that research. The situation can be summarised by the following citation:

“In science, the importance of our viewpoint when examining information of any kind cannot be too strongly emphasized, for how we look at a thing determines what we see” (Rothchild, 2006, p.5). It has also been recognised that *“The scientific community tends to be hostile to attacks on authority”*. (Rothchild, 2006, p.7).

In recent times matters to be taken into consideration for Evidence Based Practice have been expanded and the hierarchy of evidence to guide practitioners has been re-ordered.

Evidence Based Medicine was hailed as a new paradigm in 1992 and a more refined model with three distinct but overlapping sources of data that might be used when making clinical decisions emerged in 1996. This ‘three circles’ model has been adapted for use by other major health disciplines [Satterfield et al 2009 p.371]. The three overlapping circles model is also applied in other fields such as management theory and professional development.

The three circles model provided the definition used by Speech Pathology Australia in their position paper Evidence Based Speech Pathology Practice for Individuals with Autism Spectrum Disorder Practice [SPA 2009] which says in part “Implicit in the notion of evidence based practice is the integration of the clinician’s clinical expertise with the preference of each individual client and the best available evidence from systematic research”

FCT has continued to be applied but, especially in the USA and within Australia in Victoria and more recently in Queensland, has been under constant attack by supporters of the old orthodoxy.

My association is aware of Speech Pathologists who provided and supported FCT feeling such pressure that they have adopted a low profile and even left the profession in Queensland. We are also aware of instances where access to FCT has been withdrawn by state government officers, in direct contradiction of the government's extant policy.

Aside from the reliance upon the reports of original research the other consistent factor in any recent Australian consideration of FCT has been to ignore or denigrate research that does not support the orthodox position to the point where in Queensland an independent review of AACs and most particularly FCT [commissioned by the previous Labor government] resulted in a number of contradictory findings:

- The Practice Guidelines and procedural documents developed by the department in the 1990s and re-confirmed in 2005 were sound and covered situations where contentious issues were raised by users;
- FCT worked for some people with CCN issues; BUT
- The reviewers recommended that the department phase out the use of FCT for clients under its care and control.

The current government has withdrawn the report and my Association has been advised by the Disability Policy Advisor that there is no intention to adopt the recommendations of the report

The report was 'taken down' from the government web site for undisclosed reasons but had been available for a number of weeks prior to this occurring. This had allowed interested parties to download the report for detailed analysis.

The Background Paper and Appendices to this submission take the form of an analysis of the forms of evidence that contribute to evidence based practice of FCT and a response to some of the spurious arguments used against FCT.

That analysis will also detail numerous instances where the independent reviewers were either provided with selective references to research that was negative on the FCT question and reliance of the reviewers for expert advice from Emeritus Professor Alan Hudson, a noted antagonist of FCT.

There appears to be confusion amongst Speech Pathologists regarding appropriate 'evidence' to support clinical decision making. In 2012 Speech Pathology Australia produced a *Clinical Guideline on Augmentative and Alternative Communication* that illustrates that confusion:

The Guideline provides a very positive exposition of the value of qualitative studies and the value of the human experience and views of stakeholders and proposes a multi-professional collaborative approach to optimise service delivery and recognises the integral role of the person with CCN needs as well as speech pathologists, allied health assistants, occupational therapists, rehabilitation engineers, physiotherapists, psychologists, teachers, direct support workers, and family members.

This multi-disciplinary approach is proposed to include a dynamic assessment process that looks at current and future options to address the needs of a person with CCN needs. All in all a very positive and responsive approach however, a special section on FCT contradicts all these principles, denies the existence of evidence that supports the proposition that FCT users have underlying movement disorders that warrant facilitation or that 'eye tracking' research confirms that a user looked at letters on a key board before any hand movement was initiated.

The Guideline even states that "Anecdotal reports by people who communicate independently and claim to have previously used FC cannot be ignored. They form the lowest level of evidence in that there is no objective means to substantiate reported benefits, and cannot be taken as generalizable evidence" (Augmentative and Alternative Communication Clinical Guidelines (2012 Speech Pathology Australia). As a result the SPA does not recommend its use.

This double standard, applied for one single AAC strategy reflects the sad state of affairs when the leading representational body for a profession ignores both recent research and the demonstrable evidence of success [in each case someone must have assisted the users who do become independent].

The worst effect of such a statement however must be that speech pathologists across Australia may deny clients the most suitable strategy to address their particular issues and needs.

Background paper

to accompany submission from:

**Queensland Facilitated
Communication Training Inc.**

to Senate Inquiry on

**Prevalence of different types of speech,
language and communication disorders
and speech pathology services in
Australia.**

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Executive Summary

This background paper has been prepared to accompany the submission from the Queensland Facilitated Communication Training Inc. to the Senate inquiry on prevalence of different types of speech, language and communication disorders and speech pathology services in Australia.

The goal of the paper is to address the current impasse regarding a communication access strategy that is considered controversial: Facilitated Communication.

Facilitated Communication (FC) is a strategy that may be useful for individuals who have complex communication needs and who have had little or no success with conventional Augmentative and Alternative Communication (AAC) support.

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)

Section 1 of this background paper acknowledges that FC is a controversial strategy and that the controversy will not easily be resolved. Differences between the parties involved are too deep and longstanding for logical discussion to take place. This impasse can only be resolved by a fresh look at the evidence, but in a world governed by “three word slogans” (in itself a three word slogan!) it is very difficult to ask anyone to look below the surface of an issue. We hope that this Senate Inquiry may provide an opportunity for a more detailed consideration of the issues, which relate to the following terms of reference:

- C the availability and adequacy of speech pathology services provided by the Commonwealth, state and local governments across health, aged care, education, disability and correctional services;
- D the provision and adequacy of private speech pathology services in Australia;
- E evidence of the social and economic cost of failing to treat communication and swallowing disorders.

Speech pathologists play a pivotal role in the assessment, intervention, monitoring, and management of clients with complex communication needs, and in this role they are required to follow an evidence-based practice (EBP) approach to their provision of AAC services (SPA, 2012). Section 2 of this paper discusses what is meant by EBP. It is extremely important to note that “*the intended emphasis of EBP rests on the shared integration of the three cornerstones*” (Schlosser, 2004) – that is, on research evidence, clinical expertise, and client needs and preferences. In the words of one commentator:

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 (Prizant, 2011, p46).

Yet in the debate over Facilitated Communication, this is what has occurred. The findings of group based experiments with fatally flawed designs have been used to shut down all consideration of other forms of evidence required for an EBP approach.

Section 3 of the paper examines the types of evidence encompassed by EBP.

Research evidence (also referred to as “external evidence”) includes the findings of both quantitative and qualitative studies. The study design chosen should be determined by the question being asked.

In some cases quantitative evidence is appropriate and reference to a “hierarchy” to determine the weight given to particular studies is useful. However this must not be used to exclude qualitative studies from consideration when appropriate. The value of qualitative evidence has been accepted by peak bodies such as Speech Pathology Australia (SPA) and the International Society for Augmentative and Alternative Communication (ISAAC). It is not, however, generally accepted in reviews of FC.

When the results of quantitative and qualitative evidence are massively at odds, as they are in relation to FC, it is not appropriate to simply label qualitative studies as a “lower form of evidence” that can be eliminated from consideration. It is vital that the dissonance is recognised as an indicator that something is amiss in the research, and that further investigation is required to resolve this.

By some definitions research or “external evidence” should also include clinician-generated evidence (“Practice Based Evidence”), although by other definitions this element is included under the heading of “clinical expertise”.

“Expert opinion” as a source of external evidence is either totally excluded from definitions of research evidence, or is included as the lowest level of evidence. Despite this, recent reviews of FC have clearly been heavily based on advice from “experts”. Given the dogmatic nature of the debate, as discussed above, this is highly inappropriate.

Other elements of EBP include “practitioner expertise” (discussed in Section 4) and “client characteristics” (discussed in Section 5). In their Position Statement on Evidence-Based Practice in Speech Pathology, Speech Pathology Australia (SPA) quotes ASHA’s definition of EBP:

An approach in which current, high-quality research evidence is integrated with practitioner expertise and client preferences and values, into the process of making clinical decisions (ASHA, 2005, p.1, quoted in SPA, 2010, p3).

Section 6 concludes the main body of the report by considering cost of failing to address the needs of this most vulnerable group. The impact is not only on individuals with literally no voice whose communication needs have not been met through conventional AAC support. It is also on their families, schools, post-school programs, and society in general. It may be counted as lost opportunities for more positive approaches to support; as increased use of restrictive practices; 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.

The Appendices provide important supportive information.

Appendix A is a response to the surprising suggestions in two recent reviews that there is no evidence of movement disorder in autism. FC assists individuals with sensory-motor problems, including some autistic individuals. There is much current evidence of sensory-motor involvement in autism. This may have been disputed two decades ago, but it is remarkable to see it questioned in recent commentary.

Appendix B provides a more detailed discussion of the fundamental flaws that render most group-based experimental studies of FC fundamentally flawed. This material supports Section 3 in the main body of the paper. The limitations of this analysis must be recognised: the author does not have the professional skills for a systematic critical appraisal of the research evidence. However professional skills are not required to see that something is seriously amiss in the experimental designs. Extensive use of reviews that merely collate the conclusions of individual studies has served to hide the fundamental flaws that render them valueless.

Appendix C provides a discussion of the impact sensory and movement differences may have on development. It is based, not on FC users, but on overlapping populations. This is consistent with recommendations for “Science Based Practice” (see Section 3.5 of the main body of the submission). This is an exploration of issues that may impact on individuals’ capacity to respond to message passing and confrontational testing – the basis of most group based experimental studies of FC users.

Appendix D explores the very important question of assessment and outcome measures in EBP. This is a matter of high importance, as the Queensland review of FC has endorsed an assessment process that, by being centrally imposed and based on *a priori* criteria, is not in accordance with EBP and violates “*recommended practice principles by precluding consideration of individual needs*” (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2003). We are advised that the State Government is not currently acting on this recommendation, however we are aware of individuals who have been subjected to the process and who have, as a result, lost access to FC support.

Appendix E addresses suggestions that FC should not be used as it may cause harm. We outline procedures that limit the potential for harm, and urge the Committee to consider the harm that may accrue if the extremely vulnerable group of individuals for whom FC may be the only communication access strategy available are denied the option.

Please recognise that this is a human rights issue. Article 21 of the UN Convention on the Rights of Persons with Disabilities reads, in part, as follows:

Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by ..:(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions ... (UN General Assembly 2007)

Australia is a signatory to this Convention and thus has an obligation to uphold the right to communicate, not limit this right to be decided by old paradigm views or flawed research.

Appendix F is a list of research recommendations made by the American Speech-Language-Hearing Association in 1994. Twenty years on, the list is largely untouched. If there has been research on the issues raised, it has not been recognised or reported in recent reviews of FC. “Experts” act as gate-keepers for research organisations and peer reviewed journals. The effect this stonewalling of FC research has had on attempts to re-examine the “evidence” **must** be recognized.

In the absence of good quality research, “best practice” provides the most detailed information available regarding the supports encompassed by FC; the characteristics of FC users; and the outcomes that may be expected from use of the strategy. Over twenty years of rigorous attention to “best practice” in Queensland places the State’s practitioners in an exemplary position to inform “formal” investigations. However it must urgently be recognized that implicit loss of Government support has already contributed to significant loss of skill and knowledge as practitioners seek alternative career paths.

1 Introduction

1.1 Paradigm and Prejudice

Debate about Facilitated Communication (FC) has been massively polarised over more than two decades. By the very nature of the debate, individuals who have strongly identified with either position will find it difficult to provide unbiased advice to any Inquiry or review. As noted by renowned twentieth century philosopher of science, Thomas Kuhn:

“When paradigms enter, as they must, into a debate about paradigm choice, their role is necessarily circular. Each group uses its own paradigm to argue in that paradigm’s defence. ... [T]he circular argument ... can not be made logical or even probabilistically compelling for those who refuse to step into the circle. The premises and values shared by the two parties to a debate over paradigms are not sufficiently extensive for that.” (Kuhn, 1962, p94.)

Why has this situation persisted in the debate about FC? It may have been reasonable to see the FC debate in terms of opposing paradigms prior to 2005, when the standard of evidence accepted by the American Psychological Association (APA) was significantly at odds with evidence-based practice (EBP) in other major health disciplines (please see Section 2.1.2). However, alignment of EBP across disciplines since 2005 (See Section 2), together with scientific advancement over the past twenty years (see Appendix A) should have made open discussion more possible. Instead most academic comment about FC still appears calculated simply to shut down debate.

A fresh look at the evidence by individuals who have not previously taken a position on FC is essential. Kuhn noted that revolutions could only be resolved:

... by men so young or so new to the crisis-ridden field that practice has committed them less deeply than most of their contemporaries to the world view and rules determined by the old paradigm (Kuhn, 1962, p144).

Kuhn’s model of scientific enquiry shows how traditional methods –what he calls “*normal science*” - are designed to maintain the *status quo*. While acknowledging that focused attention is beneficial for the advancement of normal science within a developing paradigm, the practice of ignoring outlying data must break down when “*the profession can no longer evade anomalies that subvert the existing tradition of scientific practice*”. At such times, “*extraordinary investigations*” are needed to “*lead the profession to a new set of commitments*”. These are scientific revolutions: “*the tradition-shattering complements to the tradition-bound activity of normal science*”. (Kuhn, 1962, p5-6).

I am not suggesting that a “revolution” is required before the principles behind FC can be accommodated by mainstream science. The revolution has been occurring in related areas of science for several decades. (Please see Section 3.5, Science Based Practice, and Appendices A and C for further discussion.) Regrettably, dogmatism around FC has meant that the relevance of this new research has gone unnoticed by “experts” who act as gate-keepers for the *status quo* in research organisations and peer-reviewed journals. The effect this stonewalling of FC research has had on attempts to re-examine the “evidence” **must** be acknowledged.

Since Kuhn, it has been recognised that *“In science, the importance of our viewpoint when examining information of any kind cannot be too strongly emphasized, for how we look at a thing determines what we see”* (Rothchild, 2006, p.5). It has also been recognised that *“The scientific community tends to be hostile to attacks on authority”*. (Rothchild, 2006, p.7).

This has certainly been apparent in FC research and practice, to the point that - in the words of one commentator - *“... FC is one of the best exemplars of how practice can become absolutely dissociated from empirical research”* (Mostert, 2010, p39). Yet this statement hinges on what is meant by the term “empirical research” – an issue central to the debate which I explore in Section 2.

1.2 Recent reviews of FC

There have been a number of reviews examining FC since 2011. These have been at State, National and International levels.

1.2.1 Queensland Department of Communities, Child Safety and Disabilities (DCCS)

The Queensland Department of Communities, Child Safety and Disabilities commissioned a report into its “Communication Support for People with Complex Communication Needs” policy in 2011.

The review was conducted by Professor Paul Mazerolle, Pro Vice Chancellor (Arts, Education and Law) at Griffith University and Dr Margot Legosz, Senior Research Fellow at Griffith University. I had initial concerns regarding the appointment of reviewers with no background in a disability field, however I heard encouraging accounts of their progress which suggested that evidence from diverse sources was being considered. I genuinely hoped that the reviewers were sufficiently removed from “the crisis-ridden field” to step out of the circle of influence and provide a fresh and unbiased look at the evidence.

It is extremely disappointing that this opportunity was not taken up by Mazerole and Legosz, who have relied very heavily on expert advisors because *“[t]he time frame and [Terms of Reference] for this review limited our capacity to examine the research evidence ...”* (Mazerole and Legosz, 2012, p65).

The reviewer’s reliance on expert opinion is very surprising, given the very low or non-existent status of expert opinion in the hierarchies of evidence they have cited in their report. It is explicitly excluded from the NHMRC hierarchy (NHMRC, 2000b), and included by Gillam and Gillam (2006) only at the lowest level *“... because the therapy recommendations are not based on objective data”* (Gillam and Gillam, 2006, page 308).

The Queensland report does not list the expert advisors, however it is very clear that Emeritus Professor Alan Hudson, a long-time critic of FC from Victoria, has been extremely influential in both the direction of research and in formulating the review’s recommendations.

Regarding research, most of the review’s consideration of research evidence into FC was taken from review articles – some not peer reviewed, some not in English. Regarding those that were not in English, it appears that the reviewers accessed neither the original

paper nor a translation, but simply accepted extracts or interpretations of the material provided to them as part of the submission from Emeritus Professor Alan Hudson.

In addition to these “systematic reviews”, Mazerole and Legosz comment on nine “literature reviews” ranging from peer reviewed papers to unpublished submissions to enquiries and web pages. Of these, three were authored by Emeritus Professor Alan Hudson and the information presented in respect of a fourth review (Kezuka, 2002) was drawn from Professor Hudson’s submission to the review.

This in no way represents “*a comprehensive review of national and international peer-reviewed published research*” as claimed by Mazerole and Legosz (2012, p48). Reports of individual studies (as opposed to review articles that merely collate “findings”) show that experiments were overwhelmingly based on poor understandings of what facilitated communication is (and isn’t), resulting in poor practice. Facilitators were poorly trained, “best practice” was ignored, and inappropriate subjects were selected. Experiments featured intrusive “controls” that were highly likely to alter both the support needs of the subjects and the nature of support that could be provide. At times researchers were hostile to FC. (Please see Appendix B).

The reviewers received submissions attempting to draw their attention to these issues, however the matters raised were not addressed in their report.

With respect to recommendations, Mazerole and Legosz have endorsed an assessment process recommended by Professor Hudson (Mazerole and Legosz, 2012, p12) which, as I argue in Appendix C (Section C.1), violates the principles of Augmentative and Alternative Communication (AAC) practice according to the American Speech-Language-Hearing Association (ASHA)’s Position Statement on Access to Communication Services and Supports: Concerns Regarding the Application of Restrictive “Eligibility” Policies. (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2003).

It should be noted that Mazerole and Legosz (2012), in addition to their discussion of FC (the bulk of their report) also examine issues related to AAC other than FC. It becomes clear from their discussion that FC research is held to different standards compared with other AAC research. For example:

- a lack of good quality evidence supporting AAC strategies other than FC is not seen as a barrier to their use.
- Unlike FC, there is no formal policy requirement within DCCS for collecting assessment, monitoring and outcome data for AAC other than FC.
- Outcome measures for research into AAC other than FC are likely to include behaviour change, generalization and maintenance of skills. Quantitative research addressing FC, on the other hand, is focussed almost exclusively on facilitator influence in tasks based on confrontational testing or message passing. I am unaware of any research into AACs other than FC that examines the potential for communication partners to influence the communications of individuals with CCN, despite their clearly central role in the communication process.

The review report was, for a short period, made public in response to a “Right to Information” request. Queensland stakeholders were not informed, despite repeated

requests for advice regarding progress of the review. The report was eventually discovered on the Internet quite by chance, although pages 45 and 46 (which referred to assessment tools) were not published due to a deferral of access under section 37 of the Right to Information Act 2009. Although initially advised that these pages would, eventually, be released I have since been told that the entire report has been withdrawn from public access, and that a new “Right to Information” process would be required before release of the pages could be considered.

While withdrawal of the Queensland report from public scrutiny has some benefits in limiting the dissemination of misinformation about FC, the fact that it may be influencing decisions behind closed doors is of considerable concern.

1.2.2 Victoria

The Queensland report referred to “*a parallel investigation into FC ... funded by the Department of Human Services, Victoria*” (Mazerole and Legosz, 2012, p.29-30). It advised that the Scope, a not-for-profit provider of services to people with a disability in Victoria, would undertake the review and report by the end of November 2011. The Queensland report goes on to observe: “*The current status of that review is not known. We refer to this matter in more detail in Chapter 7 and provide more information about it in Appendix 14* (Mazerole and Legosz, 2012, p.29-30).

It is important to note that no information about the Scope review has ever been made public. Chapter 7 and Appendix 14 of the Queensland report do not refer to the Scope review, but cite very prejudicial accounts of events in Victoria which had been published in the Herald Sun. These sections of the report also quote material from Professor Alan Hudson, who as noted above has been a strident critic of FC for many years and was a major contributor to the Queensland review.

It was extremely surprising to see this material in the Queensland report, as the Herald Sun had acknowledged that their articles were defamatory, removed them from its website and published an apology. I understand that a confidential out-of-court settlement was made. Linking these scurrilous reports with the unpublished Scope review gives the strong impression of an attempt to preempt the review’s outcome. It has been suggested that inclusion of this inappropriate material in Mazerole and Legosz (2012) may have contributed to the Queensland Government’s decision to withdraw the report from the public domain.

1.2.3 Speech Pathology Australia (SPA)

In 2012, SPA published a Clinical Guideline for AAC in response to “*the expansion of evidence and technology in the field*” (SPA, 2012, p11). The Guideline “*has evolved from the Speech Pathology Australia Position Paper, Augmentative and Alternative Communication (AAC) (2004)*” (SPA, 2012, p11), however unlike the earlier paper it contains a section on Facilitated Communication under the heading “Ethical Considerations” (SPA, 2012, p30-31).

Just as the Queensland review held FC research to different standards compared with other AAC research, the Section of SPA (2012) related to FC is so at odds with the rest of the document it gives the impression of having been written by different authors.

References cited are not reports of “well designed controlled trials” as implied, but reviews and commentary, peer reviewed and otherwise. The reviews summarize findings of severely flawed “controlled” studies, but do not give adequate detail to allow readers to identify the flaws. As noted in relation to the Queensland study, data derived from fundamentally flawed experiments must be disregarded - even if their designers were “aiming high” in the hierarchy of evidence. (Please see Section 3 regarding research evidence for FC.)

The tension between SPA’s comments relating to FC and the approach taken in the remainder of the clinical guideline echoes the tension seen in the field of psychology between proponents of Empirically Supported Treatments (ESTs) and those who support Evidence Based Practice in Psychology (EBPP). Note that, until the model for EBPP was proposed in 2005, psychology was profoundly out of step with Evidence Based Practice in other fields - see Section 2.1.2 below.

SPA’s Clinical Guideline concludes that “*FC remains an approach with little supportive evidence and a preponderance of evidence that contraindicates its use, and its use is not recommended*” (SPA, 2012, p30). This statement relies on an inappropriately narrow definition of “evidence”, and the studies providing the evidence have been inadequately examined.

1.2.4 International Society for Augmentative and Alternative Communication (ISAAC)

In May 2012, the International Society for Augmentative and Alternative Communication (ISAAC) sought submissions to their committee to develop a position statement on Facilitated Communication.

ISAAC has not announced the names of committee members; however they have announced the name of the Chairman: Ralf Schlosser. Dr. Schlosser co-authored a paper denouncing FC (Sigafoos & Schlosser, 2012) almost simultaneously with his appointment as Chair of this committee.

Submissions were initially restricted to quantitative peer reviewed studies addressing the question of authorship; systematic reviews of such studies; and/or appraisal of such material. This selectivity is reminiscent of the pre-2005 position on Empirically Supported Treatments (ESTs) adopted in psychology (see Section 2.1.2). However in February 2013 ISAAC called for further submissions, acknowledging that the previous limitations on evidence were inappropriate.

In December 2013 I enquired as to the progress of the review and was advised that:

The ISAAC Executive Board (EB), wanting to ensure that the review is conducted with as much due consideration as possible to ensure outcomes and conclusions that are not biased as a result of rushing the process or bringing it to a pre-emptive conclusion for the sake of meeting a previously announced deadline date, has allowed the FC Committee additional time to thoroughly complete its work (Personal correspondence, 12 December 2013).

There has been no further advice regarding the outcome of this review.

1.3 Queensland: Where to from here?

FC was introduced to Queensland in 1992 with a year-long research study commissioned by the Queensland Government. The study, led by internationally respected psychologist, Professor Tony Attwood, investigated use of FC with 28 clients of Disability Services Queensland (DSQ). Outcomes were positive and the Department continued to use FC with some of its clients.

It is regrettable that, within a few years of this seminal study, unsupervised practice became a major problem in the Department. However it is essential to recognise that this is a failure of oversight, not of the strategy itself. Significant islands of “best practice” have been maintained, refined, and taught in Queensland’s public and private sectors for more than twenty years, drawing on a range of disciplines and building on experience and practice elsewhere. This experience is enshrined in Departmental Guidelines dating from 2005 and in private sector training programs endorsed by Qld FCT Inc.

Good quality research is rare in the field of AAC. It is actively suppressed in relation to FC, due to the extreme nature of the debate over more than two decades, and consequent disconnect between research and practice.

In the absence of good quality research “best practice” provides the most detailed information available regarding the supports encompassed by FC; the characteristics of FC users; and the outcomes that may be expected from use of the strategy. The State is thus in a unique position to contribute to future, more cooperative research, which is long overdue.

It must urgently be recognized that uncertainty regarding Government and peak body support for FC has already contributed to significant loss of skill and knowledge as practitioners seek alternative career paths. Queensland’s unique position to contribute to future knowledge about FC will dissipate rapidly unless efforts are made to stem the loss of skilled practitioners to alternative career paths.

2 Evidence Based Practice

Speech Pathology Australia (SPA) states, in their Clinical Guideline for Augmentative and Alternative Communication (AAC), that SPA:

... supports an evidence based practice approach to the assessment, intervention, and outcome measurement in the provision of AAC and other supports for people with complex communication needs (Speech Pathology Australia, 2012, p.5).

What is meant by an “evidence based practice approach”? Was such an approach used by SPA when it concluded that “FC remains an approach with little supportive evidence and a preponderance of evidence that contraindicates its use, and its use is not recommended” (SPA, 2012, p30)? Was it used by Mazerole and Legosz in Queensland, when they concluded that “...there is no evidence that FC works, that FC is potentially open to abuse and that FC should not be supported by the department” (Mazerole and Legosz, 2012, p62)?

Section 2 will discuss definitions of evidence based practice. Sections 3, 4 and 5 will demonstrate that the evidence considered by SPA (2012) and by Mazerole and Legosz (2012) in relation to the efficacy of FC has not been consistent with those definitions. Appendices A, B and C provide more detailed supporting information, Appendix D discusses evidence based assessment and outcome measures, Appendix E addresses allegations that FC has the potential to cause harm, and Appendix F provides suggestions for future research.

2.1 Evidence Based Practice: Historical Perspective

2.1.1 EBP in medicine

EBP developed from Evidence Based Medicine (EBM), which was first articulated and hailed as a “new paradigm” in 1992. It was intended to:

... develop and promote an explicit and rational process for clinical decision making that deemphasized intuition and unsystematic clinical expertise while emphasizing the importance of incorporating the best research findings into clinical care (Satterfield et al, 2009, p371)

A more refined model of EBM with three “distinct but overlapping sources of data that might be used when making clinical decisions” emerged in 1996, and this “three circles” model has since been adapted for use by other major health disciplines (Satterfield et al, 2009, p371). For example, it provided the definition used by SPA in their position paper, *Evidence Based Speech Pathology Practice for Individuals with Autism Spectrum Disorder*:

Evidence based practice involves the “conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996, p.7). Implicit in the notion of evidence based practice is the integration of the clinician’s clinical expertise with the preferences of each individual client and the best available external clinical evidence from systematic research (Sackett et al., 1996) (Speech Pathology Australia, 2009, p17).

The authors of the three circles model (Haynes, Sackett, Gray, Cook, and Guyatt, 1996; Sackett et al. 1996) “explicitly stated that under certain circumstances, clinical expertise

and/or the patient's preferences may override research evidence" (Satterfield *et al*, 2009, p371). Again, they stressed that:

EBM intentionally deemphasizes the role of expert authority and instead promotes a transparent, rational decision-making process that can be taught, refined, and applied by all clinicians (Satterfield *et al*, 2009, p371).

More recent versions of this model further define "evidence" and suggest hierarchies to help EBM practitioners identify which types of research studies should be given the most weight (Satterfield *et al*, 2009).

An Australian equivalent of the "three circles" model comes from the National Health and Medical Research Council (NHMRC). The element related to "*best research evidence*" is encompassed by their "clinical practice guidelines", which are described as "*statements of 'best practice' based on a thorough evaluation of the evidence from published research studies*" (NHMRC, 2000a, page ix, NHMRC, 2000b, page vii).

The NHMRC also acknowledges the other two elements of evidence-based practice, "clinical expertise" and "patient values", as follows:

... clinical practice guidelines ... are just one element of good medical decision making, which also takes account of patients' preferences and values, clinicians' values and experience, and the availability of resources" (NHMRC, 1999, p1).

Inclusion of: "*availability of resources*" is a more recent addition to the three circles model, as discussed in Section 2.2.

2.1.2 EBP in Psychology

As noted above, in 1996 Evidence Based Medicine (EBM) adopted the "three circles" model which identified three domains to be considered in decision making. Only one of these domains related to research evidence. The model evolved over subsequent years, but the authors continued to insist that:

... although EBM includes "evidence", it is not intended to mean that evidence is the most important source of information (in contrast to patient's preferences or clinical circumstances) but, rather, a necessary but not sufficient aspect of clinical decision making (Satterfield *et al*, 2009, p373).

In contrast to this position, in the same year (1996) the American Psychological Association (APA) Task Force on Promotion and Dissemination of Psychological Procedures released a report proposing standards of research evidence that could be used to select the treatments to be included in psychology training programs – Empirically Supported Treatments (ESTs). The Task Force:

... focussed exclusively on research evidence, singling out those treatments that had the best empirical support (Satterfield *et al*, 2009, p375).

This approach arose in an effort to demonstrate the validity of psychological treatments in comparison with pharmacological treatments, however some in the profession were concerned that the criteria were too narrow to serve as a primary guide for practice, and that the approach may inappropriately restrict access to care and choice of treatment. There were also questions as to whether interventions tested under laboratory conditions with selective participant criteria would generalise well in "real world" situation, and whether a "treatment manual" approach would exclude many forms of therapy, tailored

approaches, or types of patient from consideration. (Levant, 2005; Levant and Hasan, 2008)

It was not until 2005 that the APA's Presidential Task Force on Evidence-Based Practice "noted that multiple levels of evidence and research designs could contribute to evidence-based practice" (Satterfield *et al*, 2009, p376). As a result of this significant change, the following definition was adopted by the APA in 2005:

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 (Levant, 2005).

This new model accepts that appropriate research design is determined by the nature of the research question being asked – not by pre-determined criteria for classifying the strength or otherwise of different study designs (Levant, 2005, p7. For an example of such criteria, see Silverman and Hinshaw, 2008, p5).

Please see Section 3.1 for further information on the importance of the research question in determining appropriate study design.

The 2005 model also sought to build on the EBM model "by deepening the examination of clinical expertise and broadening the consideration of patient characteristics" (Levant, 2005, p5). Please see Sections 4 and 5 (and subsections) for further discussion of these elements.

The significant differences between evidence based practice in medicine, and psychology's exclusive focus on research evidence prior to 2005, may go some way towards explaining the polarisation of views on FC. Much of the criticism of evidence for FC has originated with psychologists, and has dated from the period before the APA's 2005 apparent change of heart.

Since 2005, the relationship between ESTs and EBPP has been characterised as follows:

EBPP is the more comprehensive concept. ESTs start with the treatment and ask whether this treatment works for a certain disorder or problem under specified circumstances. EBPP starts with the patient and asks what research evidence (including relevant results from randomized clinical trials) will assist the psychologist to achieve the best outcome. In addition, ESTs are specific psychological treatments that have been shown to be efficacious in controlled clinical trials, whereas EBPP encompasses a broader range of clinical activities (e.g., psychological assessment, case formulation, therapy relationships). As such, EBPP articulates a decision making process for integrating multiple streams of research evidence, including but not limited to RCTs, into the intervention process. (Levant, 2005, p. 273, quoted in Levant and Hasan, 2008, p659).

Yet the weight given to research evidence within the EBPP decision-making process clearly varies among practitioners. The following quote from a paper written to mark the ten year anniversary of the report that introduced ESTs does not convey any loss of enthusiasm for pre-determined research design criteria:

... despite the progress, there is still considerable work that remains. ... Needless to say, we can only hope that the current generation of child and adolescent psychosocial treatment research will heed the call ... for even more sophisticated,

more rigorous, and more statistically powerful research. (Silverman and Hinshaw, 2008, p.6).

Why is it important to question how much weight should be given to research evidence? Levant and Hasan (2008) explain by reporting that:

... lists of empirically supported treatments have been referenced by a number of local, state, and federal funding agencies, who are beginning to restrict reimbursement to these treatments, as are some managed care and insurance companies (Levant and Hasan, 2008, p.658).

They go on to argue that psychologists need to define their decision-making process or:

... someone else will dictate what treatments are acceptable and what types of evidence are privileged. Psychologists will have more leverage with insurers, courts, and policy makers when APA has a clear statement asserting that psychology is a science-based profession and preserving the right for psychologists to make the final, evidence-informed decisions in clinical practice (Levant and Hasan, 2008, p.658).

Does use of the term “*a science-based profession*” suggest that the authors of this paper favour research evidence over all else? Quite the opposite: The paper reiterates the position described in the 2005 APA’s Presidential Task Force on Evidence-Based Practice, which:

aimed to affirm the importance of attending to multiple sources of research evidence and to affirm that good psychological practice based on evidence is also based on clinical expertise and patient values (Levant and Hasan, 2008, p.658).

Parallels with the FC debate should not be ignored.

2.1.3 EBP in other major health disciplines

EBP has been adopted by other major health disciplines as a means to accelerate the rate at which research is translated into practice. Satterfield *et al* (2009) suggest that much may be learned from the way different disciplines have adapted the basic “three circles” model to their own requirements, noting that:

Ultimately, the most useful evidence in a particular situation depends on the type of question asked about a specific practice or policy (Satterfield *et al*, 2009, p380-81).

We have seen that in medicine and in psychology prior to 2005, evidence was narrowly defined. Alternatively, in the behavioural and social sciences, causality is nearly always determined by several factors. As a result, evidence is likely to be broader and may be more open to input from both qualitative and quantitative studies (Satterfield *et al*, 2009).

Client characteristics are recognised as potential moderators of outcome in the psychology and social work models of EBP. Similarly, models for psychology and nursing emphasise client characteristics and preferences at the decision-making stage, while the social work model demands more attention to institutional and environmental contexts. In a public health context, the model has been modified to address the question of how resource availability influences decision making (Satterfield *et al*, 2009).

2.2 The Transdisciplinary Model of EBP

Satterfield *et al* (2009) propose a unified, transdisciplinary EBP model in recognition that:

The challenges associated with translational science and interprofessional practice are substantial and call for more unified practice models, a common language, and unifying goals (Satterfield *et al*, 2009, p369).

The transdisciplinary model adds an “*environment and organisational context*” frame around the “three circles”. The frame:

... contains a cultural context that moderates the acceptability of an intervention, its feasibility, and the balance between fidelity and adaptation that is needed for effective implementation (Satterfield *et al*, 2009, p382).

In part this recognises that, to a greater or lesser extent in different disciplines, the feasibility of practice recommendations are modified by governing policies. This is particularly important in social science disciplines with a population focus. When practice is focussed on individual patients (as is the case in Speech Pathology, and particularly in AAC), more emphasis will be placed on the patient’s and provider’s characteristics and less on context (Satterfield *et al*, 2009).

Within this contextual frame, “best available research evidence” is now defined as:

Research findings derived from the systematic collection of data through observation and experimentation and the formulation of questions and testing of hypotheses (Satterfield *et al*, 2009, p383).

In the context of FC research, it is important to note that this description includes both observational and experimental evidence.

The circle containing “patient’s preferences” becomes “*client’s/ population’s characteristics, state, needs, values and preferences*” (Satterfield *et al*, 2009, p382).

The third circle has become “*resources, including practitioner’s expertise*” (Satterfield *et al*, 2009, p382). Practitioner’s expertise is more closely defined that it has been in EBM models, and includes “*competence at performing the EBP process, assessment, communication/ collaboration and engagement/ intervention*” (Satterfield *et al*, 2009, p383). Clinical experience in a particular intervention or technique is specifically recognised as a potentially rare resource.

“Decision-making” is at the intersection points of the three circles – a central position occupied by “clinical expertise” in a previous EBM model (Haynes, Devereaux, and Guyatt, 2002, cited in Satterfield *et al*, 2009, p372). One reason for moving decision-making to the centre of the model and practitioner’s expertise to a lower circle is that the authors:

... found that decision-making was not a particular individual’s inherent professional or intuitive skill but, rather, a systematic decisional process combining evidence with the client, resources, and context. (Satterfield *et al*, 2009, p383).

By placing decision-making at the centre of the model, the authors sought to demonstrate the difficulties and practical challenges to be faced in situations where, for example, the

evidence is at odds with a patient's or a population's preferences, or where adequate resources (including expertise) are not available. They suggest that:

By highlighting the nuances of data collection and decision making in the various disciplines (e.g., elevating patients' preferences in nursing, more heavily weighting quantitative research evidence in medicine), and providing a transdisciplinary model that represents equally all the various inputs, a practitioner using the new EBP model can more collaboratively discuss the conflicts at hand. Moreover, the emergence of these conflicts may help policymakers direct resources to providers' training, patients' education, and communities' development (Satterfield et al, 2009, p383).

As we have seen, the Transdisciplinary Model of EBP was developed through examination of EBP models in medicine, nursing, psychology, social work, and public health – but not in Speech Pathology. In the search for more explicit guidance as to how sources of data may be integrated in AAC practice, examination of a model designed specifically for Speech Pathology may be informative.

2.3 Evidence Based Practice in Speech Pathology contexts

Speech Pathology Australia's Clinical Guideline for Augmentative and Alternative Communication (AAC) note that a collaborative multidisciplinary team approach is required for optimum service delivery (SPA, 2012, p16). In keeping with this approach, the Guideline refers readers to the Transdisciplinary Model of Evidence Based Practice, (Satterfield, et al., 2009).

In the earlier "Position Statement on Evidence-Based Practice in Speech Pathology", Speech Pathology Australia (SPA) quotes ASHA's definition of EBP:

An approach in which current, high-quality research evidence is integrated with practitioner expertise and client preferences and values, into the process of making clinical decisions (ASHA, 2005, p.1, quoted in SPA, 2010, p3).

The Position Paper goes on to refer to "[r]ecently developed models of evidence-based practice" which "suggest that speech pathologists undertake a defined process when determining appropriate treatment for clients" (SPA, 2010, page 4). Three such models are mentioned, but only one is discussed in detail: Gillam and Gillam (2006), "a readily accessible evidence based practice process" (Speech Pathology Australia, 2010, page 5).

The Gillam and Gillam model of EBP adopts a five level hierarchy for assessing published research evidence – what they call "external evidence" - from the Oxford Centre for Evidence-Based Medicine (2001). In brief, the major difference between the Oxford hierarchy and that proposed by the NHMRC in Australia is that the Oxford hierarchy includes expert opinion (expert committee reports, conference proceedings, and/or opinions of respected authorities) as the lowest form of external evidence (Level 5), while the NHMRC explicitly excludes expert opinion.

In addition to the hierarchy for external evidence, Gillam and Gillam's model offers a parallel hierarchy for internal evidence – that is, evidence related to client factors and evidence related to practitioner/ agency factors – as an aid to integrating evidence from the three domains. Table One presents the hierarchy of external and internal evidence suggested by Gillam and Gillam (2006).

Table One: Model of EBP providing rating scales to assist integration of external and internal evidence

	External Evidence – published research	Internal evidence – student-parent factors	Internal evidence – clinician/ agency factors
Level I	Randomly controlled trials (RCT) and systematic reviews (SR) of RCTs.	Cultural values	n/a
Level II	Nonrandomised studies, multiple-baseline studies designs, and SRs of such studies.	Student-parent activities and participation.	Education: prior knowledge and skills.
Level III	Studies of multiple cases who received the same treatment.	Family financial resources.	Agency policies and financial resources.
Level IV	Single case studies.	Amount of interest and engagement	Clinical data
Level V	Expert opinion.	opinions	Theoretical orientation and recommendations

Source: Adapted from Gillam and Gillam, 2006

Gillam and Gillam note that:

... the system we suggest for assigning weights to clinician and agency factors may or may not apply to a variety of circumstances or caseloads. Clinicians should decide on a weighting scale that best fits the settings they work in (Gillam and Gillam, 2006, p. 309)

Thus, assigning weights to internal evidence may be more subjective than rating external evidence, although it is important to note that the latter remains subject to critical evaluation for validity, regardless of its position in any “hierarchy of evidence”.

It is also important to note that Gillam and Gillam place the authority to vary the weighting scale for internal evidence with the clinicians who are seeking to make evidence-based decisions. Gillam and Gillam encourage clinicians to trust their judgement based on their own prior knowledge and skills in the EBP process. They rate such judgement at Level II, above agency policies (Level III), clinical data (Level III and IV), and theoretical orientation and the recommendations of experts and of other clinicians whom they respect (Level V).

SPA refers to Gillam and Gillam quite extensively in their Position Paper (SPA, 2010) without suggesting any modification of their rating scale, suggesting general acceptance of the proposed ratings.

2.4 Evidence Based Practice in Facilitated Communication

At the start of Section 2, I questioned whether Mazerole and Legosz (2012) had applied an EBP approach when they concluded that “...*there is no evidence that FC works, that FC is potentially open to abuse and that FC should not be supported by the department*” (Mazerole and Legosz, 2012, p62)?

Similarly, I asked whether EBP had been used by SPA when it concluded that “*FC remains an approach with little supportive evidence and a preponderance of evidence that contraindicates its use, and its use is not recommended*” (SPA, 2012, p30)?

Mazerole and Legosz (2012) drew heavily on the NHMRC hierarchy in their review, but made little mention of other elements of EBP. Although Chapter Three of their report is titled “*Evidence based practice in speech pathology*”, it omits a definition of EBP until the summary at the end of the chapter. That definition is as follows:

... EBP for AACs has been defined as ‘the integration of best and current research evidence with clinical/educational expertise and relevant stakeholder perspectives, in order to facilitate decisions about assessment and intervention that are deemed effective and efficient for a given direct stakeholder (Schlosser & Raghavendra, 2004, p.3, quoted in Mazerole and Legosz, 2012, p.47)

The reviewers’ comment on this definition, that: “*In other words, practice is still not based entirely on research results*” (Mazerole and Legosz, 2012, p47), makes it clear that they either do not understand or do not accept the “three circles” model of EBP. Their focus on a hierarchy of research evidence is reminiscent of the psychologists who favour ESTs over EBPP (see Section 2.1.2) – however as discussed in Section 3 and in Appendix B, without rigorous attention to validity of the research.

A similar tension may be seen in AAC literature quoted in SPA’s Clinical Guideline:

On the basis of a review of the AAC evidence base, Iacono (2004) concluded that:

- *the evidence in AAC predominantly stems from single case and small group designs;*
- *research studies have been more numerous in relation to developmental than acquired disabilities;*
- *it is difficult to conduct randomised group control studies in the field of AAC due to the heterogeneity of the AAC population;*
- *the applicability of randomised control study designs to people with complex communication needs is questionable; and*
- *there is a wide range of evidence sufficient to support the application of AAC, with evidence for some areas of AAC being particularly strong as a result of controlled trials and availability of systematic reviews (SPA, 2012, p.15)*

The third and fourth points recognise the difficulty and question the applicability of randomised group control studies due to the heterogeneity of the populations. In contrast, the final point states that controlled trials and systematic reviews provide strong evidence. Please see Section 3 and Appendix B for a discussion of research evidence.

Rejection of all but research evidence is dramatically out of step with EBP in Australia and overseas. In the words of one commentator:

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 (Prizant, 2011, p46).

Although the approach taken by SPA is less transparent, a reading of the reviews and commentary cited by the authors again reveals alliance with the sentiment that clinical practice should be based on evidence from experiments which test “*the impact of an intervention under highly regulated circumstances, controlling for confounding variables that can negatively influence the findings*” (Lof, 2011, p193).

As Section 2 has sought to demonstrate, this is not an EBP approach.

3 Research Evidence

3.1 Which research designs are appropriate?

In her invited keynote address to the 2009 SPA National Conference, Laura M. Justice stated:

While some persons might argue that certain types of research methods are more rigorous than other methods (e.g. that a meta-analysis is more rigorous than, say, a survey), or that some forms of research provide stronger forms or higher levels of evidence than others (e.g. that experimentation is a stronger form of evidence than a chart review), this is, in my opinion, a misleading and erroneous perspective. Any one of these research methods can be done rigorously or weakly, and any one of these research methods can offer strong or weak forms of evidence. What is more important to consider when examining a particular work of science is whether the method used (e.g. chart review, experimentation) is appropriately aligned to the scientific question being answered (Justice, 2010, p 81 – emphasis added).

In quantitative research questions are, by definition, narrow, specific, measurable, and related to observable phenomena. This is because the research is aimed at explaining or predicting precise relationships between narrowly defined variables.

In contrast, research questions in qualitative research are more open-ended, aimed at exploring and understanding the nature of the central phenomenon. The intent or purpose of a qualitative study and the questions asked by the researcher may change during the process of an enquiry based on emerging findings (Creswell, 2002).

According to the NHMRC:

A well-formulated question generally has three parts:

- *The study factor (e.g. the intervention, diagnostic test, or exposure)*
- *The population (the disease group or a spectrum of the well population); and*
- *The outcomes.*

Since we will often be interested in all outcomes, the first two parts of the question may be sufficient (NHMRC, 2000a, p.13).

In the context of FC, none of these three factors has yet been defined in a manner adequate for well-designed experimentation. This is not to say that “narrowly defined variables” will not be identifiable – only that significant qualitative research into the dynamics of the support provided through FC will be required before they can be adequately defined for the purpose of controlled, quantitative study.

3.1.1 Defining the “Study Factor”

As noted above, the “study factor” is “*the intervention, diagnostic test, or exposure*” (NHMRC, 2000a, p.13). In FC research, the study factor relates to the complex, person-centred supports that make up the strategy, and the way in which they are flexibly applied by skilled facilitators.

I have argued in Section 3.2 and Appendix B that the procedures implemented and subjected to investigation in the vast bulk of FC experimental studies to date bear only

superficial resemblance to the strategy as clinically practiced. It is not possible to draw any conclusion about FC “best practice” from such studies.

If the fundamental nature of FC is to be understood in the detail required for experimental studies, significant attention must be devoted to identifying the elements of clinical “best practice”. This can only be achieved through qualitative research.

3.1.2 Defining the “population”

The “population” is described as “*the disease group or a spectrum of the well population*” (NHMRC, 2000a, p.13). In FC research, the population is made up of individuals who may benefit from FC. However, the characteristics of this group have not adequately been defined in a manner that allows clear delineation of the sample frame.

This has been a glaring flaw in most quantitative studies to date. Please see my comments regarding selection of subjects for experimental studies of FC in Appendix B, Section B.3.

This issue has been recognized in peer reviewed AAC literature. For example, Higginbotham and Bedrosian (1995) note that:

In the case of persons who are communicatively impaired, it is generally agreed that AAC users comprise a rather heterogeneous group of individuals, and the possession of some sort of communication disability and use of a communication technology may be their only commonalities. When AAC users are incorporated in research without stringent subject-selection criteria, investigators frequently are presented with a highly diverse set of performance-related factors (e.g., sensory, perceptual, and physical status; language and cognitive skills; educational level), making the results difficult to interpret and generalize Even when such studies produce statistically or clinically significant findings, it is difficult to relate these findings to other individuals, particularly if they do not share the same characteristics of the subjects studied. (Higginbotham and Bedrosian, 1995, p11).

Similarly:

When considering possible research designs, the use of group-level designs involving AAC subjects has often been criticized ... due to the potential limitations in the homogeneity of the subjects participating. ... Because of the relatively low incidence of AAC users in the general population, it is frequently difficult to find enough subjects required for a particular group-level research design who also can meet the subject-selection criteria needed to resolve the research question posed (Higginbotham and Bedrosian, 1995, p12).

In a related consideration, it is impossible to calculate the size of a population if the characteristics of the population have not been refined. Without knowing the size of the population, it will be impossible to identify what proportion of the population is represented by the sample. This clearly presents problems in group research, as it will not be possible to quantify measures of confidence or the statistical significance of outcomes of random controlled trials, should they be attempted.

Chapter Two of the Queensland Report (Mazerole and Legosz, 2012), titled “How to Assess Research Evidence”, is dominated by discussion of randomly controlled trials. This may give an uninformed reader the impression that there have been randomly controlled studies of FC. It is important to note that there have been no studies of FC in which subjects have been chosen randomly from an appropriate population or sample frame, nor randomly allocated to study or control groups. Such an experimental design would be impossible without clear delineation of the population.

Most quasi-experimental studies of FC to date have a very small number of participants who have certainly not been randomly selected or allocated to treatment groups. As such, these studies are highly subject to systematic error, random variation, and confounding factors (Mazerole and Legosz, 2012, pp37-38).

3.1.3 Defining the “outcomes”

With regard to “*the outcomes*”, controlled quasi-experiments investigating FC have not been “*interested in all outcomes*”, but have focused almost exclusively on the question of authorship.

In contrast, qualitative studies have examined a wide range of questions, including the impact of testing in contrived situations, the qualities of good facilitators, how “facilitator influence” may be reduced, the impact of FC on people’s lives, and so on.

Ironically, the serious flaws that render most quasi-experimental designs to date invalid cannot be addressed without the type of information that may be gleaned from qualitative studies.

With regard to autism research, Prizant notes that - despite advances in identifying genetic and neurological aspects of ASD - the condition is still recognised as a behavioural syndrome, not a disease. Interventions are not generally aimed at the neurological basis, but rather address core behavioural differences or deficits in adaptive skills. As there is significant and ongoing disagreement regarding the nature of these differences and deficits, appropriate means of measuring success is also contested (Prizant, 2011).

3.1.4 “Is ‘authorship’ the right question?”

It has been noted that:

All of the naturalistic studies have reported positive changes in the communication skills of individuals following the introduction of FC. Experimental research, on the other hand, has focused almost exclusively on issues related to validation and authorship. (ASHA 1994, quoted in Mazerole and Legosz, 2012, p.55).

Most experimental studies designed to investigate FC demonstrate little more than the widely accepted facts that FC users have difficulty passing messages in contrived circumstances, and that facilitators can influence communications. But is “authorship” the right question? ASHA (1994) also identified extensive gaps in the research which remain highly relevant. I have reproduced the research recommendations in full in Appendix F. To date there has been little, if any, progress on most of these questions.

Pioneering child development researcher Vygotsky (1978) proposed that learning occurs through socially mediated scaffolding in the “zone of proximal development” - that is, the zone between a learner’s current problem solving ability and the level of ability he or she could achieve under adult guidance or in collaboration with more capable peers (Magliaro, Lockee, Burton, 2005, p51.). FC may be a means by which some individuals can engage in more complex and sustained social interactions and thereby access “the zone”. By definition, communication in the zone of proximal development may be significantly influenced by communication partners. This is not, to my understanding, thought to render the efforts of the student valueless. That is, apparently, unless they are FC users.

Prizant, Wetherby, & Rydell (2000) make the following comment regarding the nature of intervention most likely to produce real benefit in the cognitive development of autistic individuals:

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.)

For elaboration of this developmental viewpoint, please see my comments in Appendix D, Section D6 regarding what the reviewers have referred to as the “confounding factor”.

I do recognise that problems may arise when testing, rather than teaching, becomes the objective of an activity. The practice of scaffolded learning is very different from a testing process intended to identify the skills an individuals can demonstrate without scaffolding. However, the fact this is a challenge should not be used as an excuse for excluding individuals with severe communication impairment from enriched learning and training opportunities. **Such issues are a challenge that must be addressed by educators and researchers. They should not be made the learners’ problem.**

Please see Appendix B, Section B.7.5, which addresses assertions that FC users are passive intermediaries for facilitator influence.

Regarding AACs other than FC, the Queensland review notes:

ASHA emphasises the importance of communication partners: they can facilitate the successful implementation of an AAC by providing individuals with emotional, conversational and technological support. An effective AAC requires commitment from all social partners, including family members, professional staff and peers. Communication partner’ responses (such as the rate of response, quality of reinforcement, response effort and immediacy of reinforcement) will reinforce various practices, including responses to different styles of communication to the preferred option. ASHA also identifies communication partners as potential barriers to communication if they fail to understand the importance of their role (Mazerole and Legosz, 2012, p.98)

I am unaware of any research into AACs other than FC that examines the potential for communication partners to influence the communications of individuals with CCN, despite their clearly central role in the communication process.

Facilitator training includes explicit attention to discourse analysis, designed to ensure that communication partners are aware of, and thus equipped to avoid, implicit power imbalance in interactions. Without such awareness, communication may be severely compromised.

3.2 Quantitative Research

Superficially, it would seem that consistent conclusions from study designs high in a “hierarchy of research evidence” are likely to trump the conclusions of lower level studies. Green and Shane (1994, p.163) observed that:

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.

There was certainly consistency in the results obtained from “controlled” experimental studies of FC conducted during the 1990s and, to a lesser extent, since 2000. Very significantly, however, there was also an unfortunate consistency in the design of experiments, with heavy emphasis on confrontational testing or message passing in highly contrived circumstances. As such, it absolutely cannot be said that the experiments were “*each using somewhat different methods and flawed in different ways*”. Convergence of evidence based on experiments that essentially use the same flawed methodology does not warrant strong conclusions.

While it is accepted that the “*type*” of study – that is, its level in a “hierarchy of evidence” such as those proposed by the Oxford Centre for Evidence-Based Medicine (2001) or by NHMRC (2000b) - is an important consideration, systematic examination of each study for threats to validity is essential. This has not been undertaken in the FC debate.

Data derived from fundamentally flawed experiments must be disregarded, even if their designers were “aiming high” in the hierarchy.

In her keynote address to the SPA National Conference in 2009, Laura M. Justice said:

*[I]t is very important that empirical evidence used to inform clinical decision-making is subjected to scrutiny. In fact, engaging in evidence-based practice means that one does not just take any scientific report at face value; rather, it involves **evaluating the quality of the science to determine whether it is of sufficient quantity and quality to influence ones clinical decision making** (Justice, 2010, p.81- emphasis added).*

Put simply when, as is the case in the FC research, there is a massive difference between conclusions drawn from experimental and those from observational studies, it is clearly necessary to examine the full range of research designs for clues as to what may be amiss.

3.2.1 Confrontational testing/ Message passing

The most significant defect in most quantitative investigations of FC to date has been that experimental designs test only the participants' ability to pass messages, not their capacity for other forms of communication, such as self-motivated communication on topics of their own choice. Basing a test of the ability to communicate on a task that is so demonstrably problematic for a large proportion of the test population *must* be questioned. I am unaware of any evidence, nor any attempt to demonstrate, that confrontational testing or message passing are valid tests of an individual's capacity for other forms of communication.

Some speculate that difficulties with message passing may be due to a lack of opportunity to practice and shape the behaviour through the innumerable reciprocal interactions available to verbal children. Others wonder if the answer may be more complex, grounded in the sensory and movement difficulties that characterize this population. For further exploration of this second possibility, please see Appendix C, Science Based Practice. Regardless of the reason, testing FC users' ability to communicate using a task that is so clearly problematic for many *must* be questioned.

Alternative means of evaluating FC have been identified and used in other studies. Examples include use of specialist eye-tracking equipment and fine-grained video analysis to demonstrate that an FC user was making visually guided, intentional movements towards the letters he selected (Grayson, Emerson, Howard-Jones and O'Neil, 2011); and statistical analysis of texts to identify distinctive lexical features (e.g. Bernardi & Tuzzi, 2011a). (Please see Section 3.2.5.) It is recognised that these alternative experimental designs may not be suitable for application across the whole population of FC users – due, for example, to visual differences that may affect some individuals (e.g. see Yoshida, Nakamizo, & Kondo, 2011) or to different levels of literacy within the FC user population – however **the pressure to overcome such difficulties must be on those who design experiments, not on the subjects.**

By rejecting confrontational testing or message passing as legitimate bases for experimental designs, I am not suggesting that FC users should not be assisted to develop the skills needed for these tasks – only that the focus must be on teaching, not testing. I *would* argue that interventions must address underlying mechanisms, rather than teaching the skill in relative isolation. However, research is needed to clarify what the underlying mechanisms may be, and such research is unlikely to proceed while the communications of FC users are not accepted as genuine reflections of their cognitive processes.

3.2.2 Basic experimental design

In addition to questions related to confrontational testing and message passing, other aspects of the 1990s experimental designs were antithetical to the strategy of facilitated communication. As a result, the procedures implemented and subjected to investigation bore only superficial resemblance to FC. It is not possible to draw any conclusion about FC “best practice” from such studies.

FC is a strategy designed to provide environmental, physical and interactional/emotional support to individuals who have severe communication impairments. Facilitators “presume competence” to build confidence (e.g. see Biklen & Burke, 2006). Confrontational testing and removal of supports under the guise of “experimental controls” is highly likely to create anxiety and to create barriers to communication,

particularly for vulnerable participants. Add to this intrusive controls, poor practice, poorly trained facilitators, inappropriate selection of subjects, and hostile researchers. (See Appendix B for more detail of the flaws in experimental design.)

In short, while research from the 1990s – the bulk of “controlled studies” to date - may have reflected the state of knowledge and regional differences at the time, it is by no means comparable with – and therefore cannot be taken as commentary on – current “best practice” in facilitated communication.

Remarkably, despite their flaws, some controlled studies did provide a level of support for Facilitated Communication. These included Calculator and Singer (1992); Calculator and Hatch (1995); Bebko, Perry and Bryson (1996); Cardinal, Hanson, Wakeham (1996); Heckler (1994); Sheehan & Matuoizzi (1996); Vazquez, (1995); and Weiss, Wagner, & Bauman (1996). Also, please also see comments in Section 3.2.3 regarding data collated in reviews.

It is recognised that the supportive evidence these studies provide is quite limited. While perhaps adequate to “falsify” bald assertions that “*FC does not work*” (e.g. Lof, 2011. p192), it certainly does not match the impressive results reported from observational studies. None-the-less, the fact that any supportive evidence at all was produced in the face of severely flawed experimental designs must be acknowledged as quite an achievement.

(As an aside, it may be worth noting the limitations of a strictly hypothetico-deductive model of scientific enquiry. No-one is suggesting that “FC always works”. Finding that it does not work for many individuals will not falsify a hypothesis that it may work for some individuals - so essentially that is not a testable hypothesis in this model of scientific enquiry.)

FC proponents, at times, went to great lengths in the attempt to comply with the demands of experimental design, for example providing FC users with:

“... extensive practice with test taking (i.e. the process, not content); extensive time for response; feedback to participants on how they are doing with the tests; multiple choice format to remove word retrieval and/ or short-term memory difficulty; and opportunities for participants to inform the research process with their ideas about the conditions under which they might succeed.” Biklen and Duchan 1994, p178.

Far from convincing critics, such efforts have resulted in responses such as the following:
“If FC users can only communicate in “ultranatural” situations in which it is somehow inferred that they feel very confident and then can produce only well-rehearsed words, it is difficult to see how FC can be a functional, generally useful method of communication for them.” (Green and Shane 1994, p157)

(Note: FC is not about reproducing “well-rehearsed words”.)

In the face of such experience, it is not surprising that proponents of FC tend to eschew “controlled studies” in favour of more naturalistic approaches. It is my personal opinion that FC users should not be trained simply to comply with a flawed experimental design. Such an approach suggests that we accept the premise of the experimental design, which I, for one, do not.

3.2.3 Systematic Reviews

It is important to note that reviews compile lists of the results and conclusions of studies without providing details of experimental design and method. Examination of individual studies is essential to reveal the major flaws that may render their results and conclusions meaningless. Collections of conclusions from studies based on experimental practices that bear only superficial resemblance to FC, and which test only one aspect of communication, are as invalid as the studies they have been based on.

With regard to the recent Queensland review of FC, as noted in Section 1.2.1 the reviews cited were of mixed quality. I have been able to access only four (Green, 1994; Jacobsen, Mulick and Schwartz, 1995; Simpson and Miles 1995; and Mostert 2001) and note that the only studies subjected to detailed criticism were those that found evidence in favour of FC. Clearly this selectivity is inappropriate. As noted by Tehan & Senior:

There is bias evident in the reviews to the extent that the reviews critically evaluate only the studies in which positive effects of FC have been obtained; very little attention is paid to the methodology or the validity of the results of the studies where negative effects have been found (Tehan & Senior, 2006, p12).

Surprisingly, the Queensland review lists some results that may be interpreted as support for the suggestion that FC may work for some individuals (Mazerole and Legosz, 2012, pp 49 to 55). The following provides combined results for quantitative, controlled studies, showing at least some validation of FC. (I have not included results for studies without controls in this list):

- Green, 1992: 12 studies, three out of 146 possible responses possibly attributed to FC.
- Green, 1994: 25 studies, 12 out of 226 possible responses possibly attributed to FC
- Jacobsen, Mulick and Schwartz, 1995, 15 studies, 126 subjects, 4 possible instances of FC success.
- Simpson and Miles, 1995, 14 studies, 43 tasks, 2 possible instances of “FC effect”.
- Gorman, 1999: 21 studies, 210 trials, 21 cases of validation.
- Mostert, 2001, 25 controlled studies, 72 conclusion drawn, 10 support FC.
- Senechal Larivee and Richard, 2004, 35 studies, 6% of subjects show capacity to communicate.
- Probst, 2005, 37 clinical studies, 343 subjects, no figure given for validations. (Source: Mazerole and Legosz, 2012, p.49 to 55).

The fact that any supportive evidence at all was produced in the face of severely flawed experimental designs is remarkable. I make no further comment, as I hope I have made it clear that I do not accept the validity of “systematic reviews” that have not critically examined the studies they include for “threats to validity”.

3.2.5 Recent advances in study design

After a decade during which very few controlled experiments were attempted, new research designs are now emerging. These generally represent efforts to design a more rigorous, more quantitative approach which can none-the-less be applied in a less intrusive way than was seen in 1990s experiments. Although not all FC users may be

suitable candidates for the new designs, these studies do demonstrate that it is possible to overcome some of the problems associated with previous experimental design.

One recent peer reviewed study (Grayson et al, 2011) was designed to yield “*reliable quantifications of behaviour ... fully open to peer review, while minimising interference in the very processes that are under investigation*” (Grayson et al, 2011, p2).

This systematic observational inquiry used specialist eye-tracking equipment and fine-grained video analysis to demonstrate that an FC user was making visually guided, intentional movements towards the letters he selected – that is, that he was not being controlled by his facilitator. (Grayson et al, 2011, p2).

While the authors of this study acknowledged that such finding cannot automatically be extended to other FC users, they have successfully demonstrated a rigorous design capable of avoiding the more serious flaws of past experiments. For example, one particularly significant aspect of this study was that most of the data collected were from free-form conversations, not responses to set questions.

It should be noted that the FC user in this study has previously “failed” formal message-passing tests, lending credibility to assertions that such tests are not always appropriate for evaluating the efficacy of FC. (Grayson et al, 2011)

Grayson et al (2011) augment their quantitative data with qualitative observations of their subject’s behaviour. For example, they note that he is not a compliant person, and would not normally sit for hours in a hot room filled with monitors, cameras and computers, in close proximity to others, wearing a sensor on his head and allowing his hand to be supported.

Why would this man sit for so long making (what to the sceptical viewpoint are) meaningless ballistic movements towards a screen sparsely covered with uninteresting, neutrally coloured static shapes, while all the time attending to the screen and consistently following the movement of his finger around it with his eyes?” (Grayson et al, 2011, p13)

A large Italian study has taken a different approach: a statistical analysis of texts generated at FC sessions to identify distinctive lexical features. Various aspects of the study have been reported in Bernardi & Tuzzi (2011a), Bernardi and Tuzzi (2011b), and Tuzzi (2009). Cluster analysis shows that the texts written by FC users in this study were similar to each other and different from those produced by their facilitators (which also resembled each other). Texts produced by FC users were more complex in terms of lexis and of morphological and syntactic structures. Grammatical categories (nouns, adjectives, verbs, adverbs, etc.) show a particular distribution and particular syntactic structures tend to emerge, such as more frequent use of modifiers and omission of grammatical words (prepositions, conjunctions, articles, pronouns) when this does not hamper the understanding of the sentence’s meaning.

Mazerole and Legosz (2012) view Grayson et al (2011) promising. They do not, however, appear to accept it as evidence that FC may “work” for some individuals. Rather, they state:

This study is noteworthy and complies with the impression that we have formed that something within the FC environment (a confounding factor) may work (Mazerole and Legosz, 2012, p62)

Please see Appendix D, Section D.6 for my comments regarding what the reviewers refer to as a “confounding factor”.

Regarding Bernadi and Tuzzi (2011a), Mazerole and Legosz state:

... it is the view of the research team that the study does not answer the critical and most significant element in FC research, i.e. authorship. It also fails to control for systematic bias in facilitator influence (Mazerole and Legosz, 2012, p60).

The reviewers have not discussed their reasons for rejecting the researchers’ interpretation of the data. Similarly, they have not supported their statement that the study “*fails to control for systematic bias*”.

The statements give the impression of too easy dismissal of this important study.

Speech Pathology Australia was similarly dismissive in their Clinical Guidelines for AAC:

The continued research interest in FC remains controversial. There have been recent attempts to use sophisticated complex analyses (Bernadi & Tuzzi, 2011) and eye-gaze technology (Grayson et al., 2011), but these have failed to provide a means to authenticate messages (SPA, 2012, p30).

Such rejection without adequate explanation gives the impression that the statements reflect a belief system rather than the findings of careful research.

It is of vital importance that study design continues to evolve. As noted by Tehan & Senior (2006, p.19):

Those who support the use of FC have a wide research agenda involving most aspects of FC, from the characteristics of those who successfully employ the strategy, to attempting to understanding the neurobiology that underpins its usage, to establishing a multi-method approach to the issue of validation of communication.

If the vast array of naturalistic studies examining FC counts for anything at all, it must at least demonstrate that there is something here to study. As Isaac Asimov (the well-known US science fiction novelist & scholar) is said to have quipped:

The most exciting phrase to hear in science, the one that heralds new discoveries, is not “Eureka” but “That’s funny” ... (Kline, 2008, p236).

The onus must be on researchers, not FC users, to respond to the clear evidence that research design to date has been inadequate and inappropriate.

3.2.6 Future directions for study design

The Queensland review asserted that:

To study the effects of interventions, it is necessary to compare a group of patients or clients who have received the intervention (study group) with a comparable group who have not received the intervention (control group) (Mazerole and Legosz, 2012, page 31)

This approach may be appropriate for medical research, where carefully defined treatments can be randomly allocated to large groups of subjects drawn randomly from a well-defined study population. This is not generally the case in therapy or education research and, as noted in Section 3.1, is certainly not the case in FC research.

Single subject studies may offer an alternative to group based experiments. SPA describes n=1 trials as:

Highly methodically-controlled single case design trials that currently comprise the largest proportion of studies in some areas of clinical practice. ... As they closely mimic a clinician's work with individual clients, their importance to evidence-based practice is apparent (Speech Pathology Australia, 2010, pp4-5).

A respected textbook on research design refers to single subject research as follows:

Single-subject research (also called N of 1 research, behaviour analysis, or within-subjects research) involves the study of single individuals, their observation over a baseline period, and the administration of an intervention. This is followed by another observation after the intervention to determine if the treatment affects the outcome (Cresswell, 2002, p316).

Cresswell notes that the subject essentially becomes its own control in the experiment, but also notes that without random assignment, the design is a quasi-experimental rather than an experimental design. This **does not** render single subject design inferior to existing FC research, which as discussed in Section 3.1.2 has not to date involved randomized selection and assignment of subjects to treatment groups.

As Creswell observes:

*Single-subject research has the advantage of providing data on single individuals, such as the learning and behaviours of children with disabilities, **where a person-by-person analysis is needed**. It also controls for many threats to internal validity. Because only one individual is studied at a time, groups are not involved and the threats to selection, treatments, mortality, maturation, regression, and interactions with selection are not relevant. Assuming the researchers use the same standard procedures, instrumentation may not be a problem* (Creswell, 2002, p317 – emphasis added).

Is it valid to assert that, in some situations, “a person-by person analysis is needed”? The Queensland review appears to be equivocal on this issue. In Chapter Two it warns against a situation in which treatments “may have been offered selectively to patients in whom it is likely to succeed” (Mazerole and Legosz, 2012, 43). On the other hand, Chapter Five of the review – which deals with AAC interventions excluding FC, - includes the following quote:

One cannot generalise results from a group to any specific individual who uses AAC; rather initial trials should be conducted with the individuals to determine whether or not the individual has the necessary sensory and motor skills to use the methods in question. ... [There is] tremendous heterogeneity across the population of individuals who use AAC as well as within specific individuals at different times of the day and in different situations. (Dowden and Cook, 2002, quoted in Mazerole and Legosz, 2012, p79-80).

This is yet another example of different standards being applied to FC compared with other AAC strategies. Until there is clear understanding of the characteristics that

distinguish individuals who may benefit from FCT, “*person-by-person analysis*” is the only available approach to identifying suitable subjects. Please see Section 5, which discusses the importance of client characteristics in EBP, and Appendix B, Section B.3, regarding the flawed approach to selection of subjects in experimental studies to date.

It is none-the-less important to recognize certain drawbacks of single subject research design. Creswell notes that:

When multiple treatments are used, the learning from one intervention may affect the second intervention, and history may be an issue since the experiment takes place over time (Creswell, 2002, p317).

Creswell also warns of potential harm to subjects:

... in some studies, the withdrawing of the intervention may have serious effects on the participants in the study, raising an ethical issue for the researcher (Creswell, 2002, p317).

Ethical considerations must be at the forefront when considering research in this vulnerable population. To illustrate, Green and Shane (1994) outline an extraordinary standard of evidence that they would require before accepting that FC Training had led to independent typing. This includes:

... a solid basis for ruling out possibilities that prior learning or other instruction was responsible for the outcome (i.e. a bona fide research design) (Green and Shane, 1994, p155).

This type of attitude is probably behind the following statement from SPA’s AAC Clinical Guideline:

Anecdotal reports by people who communicate independently and claim to have previously used FC cannot be ignored. They provide the lowest level of evidence in that there is no objective means to substantiate reported benefits, and cannot be taken as generalizable evidence (SPA. 2012, p.30).

As achievement of independent access to communication is likely to take a great deal of time and effort, it is not only unreasonable – it would be unethical - to expect this to occur under controlled conditions designed to rule out influences other than FC. FC “best practice” in no way precludes the use of other supports, programs, strategies, therapies, etc. On the contrary, facilitator training places significant emphasis on collaboration with a team of professionals determined by the individual’s needs. The very important difference between controlled research and “best practice” must be recognised and potentially harmful “controls” used only briefly and with great care. Under these circumstances, quality data collected by practitioners is likely to be the most appropriate means of tracking an individual’s progress towards independence. Please see Section 3.4 regarding Practice Based Evidence.

The ASHA’s *Facilitated communication* [Technical Report] states:

Researchers in the experimental and qualitative traditions are encouraged to collaborate in order to design valid, mutually agreed-on procedures for probing validation (ASHA 1994).

Mirenda has suggested:

[W]e need to be bold – not conservative – in formulating research questions and executing studies that push existing boundaries and test hypotheses that may be unconventional but may also lead to new insights and applications.

One way to approach this task is to identify people with ASD who have become competent (and independent) communicators through the use of AAC (including FC), and then to work backwards to answer the question “Are there common factors that appear to have contributed to these good outcomes? If we find any (and I believe we will), we can then design longitudinal hypothesis-driven studies to examine these factors in natural contexts (Mirenda 2008, p229).

3.3 Qualitative Research

The Queensland review noted that:

We were ... told that traditional/formal/quantitative research methods are inappropriate for assessing FC, and indeed, that supporters of such methods simply do not understand FC or are biased (labelled sceptics) (Mazerole and Legosz, 2012, p62).

Later in the report the reviewers opined:

It would be desirable for FC users to embrace the accepted methodology for assessing interventions and engage appropriately trained researchers to examine their work in an appropriate, objective and robust manner (Mazerole and Legosz, 2012, p74).

Lof notes that scepticism is central to scientific practice. Sceptics must be open to new ideas "no matter how bizarre or counterintuitive" (Lof, 2011, p190). So, when the experimental evidence does not agree with the observational evidence, sceptics have an obligation to re-examine all the evidence, not simply to turn to “expert” opinion and the results of fundamentally flawed experiments to settle the matter. It is essential to eliminate prejudice when collecting and analysing empirical data, no matter who this may offend.

A report commissioned for Disability Services Queensland in 2006 noted that the antagonists of FC have focused almost solely on the question of authorship, while ... *[t]he proponents of FC have adopted a wide ranging agenda with respect to research aims. They have explored issues like understanding the facets of autism that prevent more traditional methods of communication being effective; the understanding of FC within a framework of movement disorders; how one facilitates the move to independent typing (pointing); authorship; and determining for whom FC is likely to be effective. (Tehan & Senior, 2006, p1)*

Most of these diverse studies fit descriptions such as observational, naturalistic, and qualitative rather than experimental, controlled and quantitative. Such evidence has often been dismissed as valueless by critics of FC, however this attitude is not consistent with more objective standpoints. The word “empirical” means “*based or acting on observation or experiment ...*” (The Australian Concise Oxford Dictionary, 1987, p338). That is, “empirical” embraces data both from controlled experiments and from careful observation under more natural circumstances. What “empirical data” is intended to be free of is prejudice and dogma based on existing “theory”.

Unfortunately prejudice and dogma have dominated the FC debate for more than two decades. Data derived from fundamentally flawed experimental designs is simply invalid. As such, it cannot claim superiority over qualitative evidence or practice based evidence.

In their position statement on Evidence-Based Practice in Speech Pathology, SPA refers to the “levels of evidence” identified by the NHMRC hierarchy. However the document notes that:

*It is also important to acknowledge that randomized control trials will not be appropriate for all research studies (see Greenhalgh, 2001, p41). Indeed, **many important and valid studies in the field of qualitative research do not feature in the hierarchy of evidence and rate poorly on the scales outlined** [by the NHMRC]. For this reason, it is important that clinical practice be informed by information obtained from different sources, including information from other levels of evidence ... (SPA, 2010, p5 – emphasis added).*

More recently, the SPA Clinical Guidelines for AAC noted the following regarding qualitative research:

The evidence base in AAC is strengthened by the conduct of rigorous qualitative studies, well suited for use in heterogeneous populations, and to gather an understanding the human experience and views of key stakeholders. In accordance with this, a strong tradition of rigorous qualitative research is building in the field of AAC and multimodal communication for understanding of all the factors and complex relationships that might exist in particular life situations Such rigorously conducted qualitative studies provide evaluations of important topic areas, inform future qualitative and quantitative research, and guide changes to policy and practice to improve the lives of people with complex communication needs (Speech Pathology Australia, 2012, p.15-16.)

In May 2012, the International Society for Augmentative and Alternative Communication (ISAAC) sought submissions to their committee to develop a position statement on Facilitated Communication. The restrictions they had initially placed on submissions essentially limited them to controlled, quantitative research. However in February 2013 they called for further submissions, acknowledging that qualitative studies and unpublished sources must be considered. Although the result of their review has not yet been announced, this acceptance of the need to consider a broader range of evidence by the International peak AAC body is not insignificant.

As noted in Section 1.2.3. The tension between SPA’s comments relating to FC and the approach taken elsewhere in the Clinical Guideline echoes the tension seen in the field of psychology between proponents of the Empirically Supported Treatments (EST) approach and those who support Evidence Based Practice in Psychology (EBPP). That being the case, the following quote from the APA’s report introducing Evidence Based Practice in Psychology may be relevant to the FC debate:

Acceptable research designs include clinical observation (as a source of innovation and hypotheses); qualitative research (to describe subjective, lived experience); systematic case studies (for comparing individual patients to others with similar characteristics); single case experimental designs (for establishing causal relationships in the context of an individual); public health and ethnographic research (for tracking the availability, utilization, and acceptance of mental health treatments, and for suggesting ways of altering them to maximize

their utility in a given social context); process-outcome studies (for identifying mechanisms of change); studies in natural settings (for assessing the ecological validity of treatments); randomised clinical trials (for drawing causal inferences about the effects of interventions) and meta-analysis (to synthesise results from multiple studies, test hypotheses, and estimate effect size) (Levant, 2005).

These statements from peak bodies in Speech Pathology, AAC and Psychology make it clear that qualitative research should not be excluded from research in their fields. Yet resistance to controlled experimentation has been described by some critics as “*strident resistance to objective evaluation and ... overemphasis on faith and subjective beliefs*” (Green and Shane, 1994, p168). On the contrary, the attitude to controlled experimentation must be seen as a rational unwillingness to participate in seriously flawed experimental designs that may have far-reaching negative impacts on FC users’ access to communication. The empirical alternatives to experimental evidence are not “*faith and subjective beliefs*”, but a range of less intrusive research methods that have more commonly – and very much more strongly - supported the efficacy of FC for more than twenty years.

Naturalistic studies supporting the efficacy of FC generally involve analysis of communications for idiosyncratic word forms or sentence structure (e.g. Niemi and Kaernae Lin, 2002) or for “*unique physical characteristics in typing or pointing, personal themes, recurring phrases, and stylistic qualities*” (e.g. Biklen, Saha, & Kliewer, 1995). Behavioural changes including improved communication (e.g. Clarkson, 1994; Janzen-Wilde, Duchan & Higginbotham, 1995) and non-verbal behaviour matching typed messages (e.g. Olney, 1995) have also been reported.

Studies by Emerson, Griffiths, Prentice, Cosham, Howard-Jones & Grayson (1998) and Emerson, Grayson & Griffiths (2001) used a range of these methods, along with intensive video analysis, to provide evidence that FC enhances the communication skills of some subjects. Significantly, subjects who had been successful in more naturalistic activities failed “message passing” tests under controlled conditions, highlighting the mismatch between the findings of naturalistic methods and those of the flawed experimental designs used throughout the 1990s and beyond.

3.4 Practice-based evidence

Loff, in his invited keynote speech at the 2010 SPA national conference, made the case for evidence-based practice in speech language pathology but modified the usual definition to replace “*clinical experience*” with “*practice-based evidence*”. He acknowledged that the “*highly regulated circumstances*” demanded for controlled studies “*make it difficult to apply the studies in the real world*”, and that “*evidence from real world clinical practice can add important data to the EBP knowledge base*” by testing “*the impact of an intervention in more typical settings and conditions*”. However, he cautioned that this was only valuable if the evidence has been “*adequately obtained*”: That “*extensive clinical experience or poorly gathered internal evidence from that experience is not a valid determiner of ‘what works’ in therapy*” (Loff, 2011, p.193).

Lof defines practice-based evidence as the contribution to evidence-based practice “*by practitioners who utilize research methodologies to critically examine the quality of their clinical practice and service*” (Loff, 2011, p.194). That is, practice-based evidence is

quality data collected by practitioners to evaluate the effectiveness of their interventions - not under experimental conditions, but in typical settings such as clinics and schools.

Lof states that a science based practitioner must not only collect data, but also analyze it for unexpected findings and question his or her practice accordingly.

It should be stressed that it would be inappropriate to consistently conduct clinical practice as if it were research. Practitioners in the social-pragmatic tradition avoid intense data collection as it is thought to interfere with “*caregivers or therapists establishing a continuous reciprocal flow and affective rhythm*” (Greenspan 2001, p37).

Despite this caveat, the need for data based decision making is acknowledged. Prizant, for example, supports introduction of emerging practices ahead of research “*as long as data-based decision-making is part of practice, and as long as the potential benefits outweigh the potential costs or risks*” (Prizant, 2011, p.47) This is necessary, he argues, given “*the current tenuous and preliminary state of treatment research in ASD*”. Too narrow a definition of EBP may inappropriately delay use of promising emerging practices. He lists Social Stories; inclusive programming in schools; visual supports; and the use of speech generating devices as practices that have been introduced and successfully implemented before research evidence of efficacy was available (Prizant, 2011).

Gillam and Gillam rate practice based evidence as follows:

The data that individual clinicians collect on the children they treat is weighted as Level 4 evidence. We believe this is consistent with Level 4 external evidence from single case studies. Over time, a clinician may collect data on 15 or 20 children who receive the same kind of treatment. This data would provide a good indication of the range of outcomes that an individual clinician obtains. Clinician-generated outcome data from many children who received the same type of treatment would be consistent with studies of multiple cases (Level 3 external evidence) (Gillam and Gillam, 2006, page 309).

FC training and “best practice” guidelines place strong emphasis on data collection and data-based decision making. This appears to be in stark contrast with more general SLP practice, described in the Queensland review as follows:

SLPs base most of their clinical decisions on information they were taught during their graduate programs, their clinical experience, and the opinions of colleagues which is contrary to the principles of EBP (Gillam and Gillam, 2006, cited in Mazerole and Legosz, 2012, p47.)

In Queensland, excellent training has been available in both the public and private spheres for two decades. Training workshops and manuals (e.g. Remington-Gurney, 2009) detail “best practice” developed to safeguard against some of the poor practices that may result in misuse of the strategy. Ideally, workshops will be augmented by competency-based, practical assessment, and within each setting and region there will be a network of facilitators trained to different levels (basic, advanced, instructor, and instructor-presenter), available to support each other’s practice.

Standardized training provides the opportunity for collection of data comparable across time, settings, facilitators and FC users. As an example of the type of data that may be collected, the amount of physical and interactional support an FC user needs is likely to

vary during any given interaction. However, as FC training progresses over time, reliance on physical support is generally expected to reduce and ability to converse at more complex levels to increase. Collection of data provides a record of progress towards these goals, and towards the ultimate goal of FC training: independent communication.

In a book published as early as 1994 (but based on even earlier established practice), Rosemary Crossley urged data collection as a means of structuring and recording success. The book – “Facilitated Communication Training” - provides examples of forms for data collection that may be used by facilitators and agencies (Crossley, 1994).

Similarly, Remington-Gurney (2009) stresses the importance of recording data, and provides model forms on which facilitators may record FC user’s progress over time and evidence that may be used to validate communications. Other forms are designed to track facilitator training, and for FC users to periodically self-assess. Standardized codes linked to information provided in facilitator training workshops maximize the comparability of data between different FC users, facilitators, setting, and times.

In personal correspondence Matthew Wilson – Senior Practitioner [Speech Language Pathology] for Queensland’s Disability Services until October 2011, said:

... In the department, the following data was recommended: Working towards independence recording sheets, Facilitator competency checklists, and recording of naturalistic validation. The conversational hierarchy and levels of physical support were used as frameworks for coding data for analysis. Discourse analysis was used to code and analyse interaction. ...

... This approach to data based decision making is also detailed in training provided at Bolton University, as well as in the best practice guidelines coordinated by the Facilitated Communication Institute (now Institute on Communication and Inclusion). It is nice to see that there is a long-standing approach to data based decision making that is being recommended in countries around the world. (Wilson, 2012)

Despite the strong emphasis on “best practice” in facilitator training, decisions about data collection and practice remain a matter for an individual FC user’s family, agency, or facility – whoever takes primary responsibility for his or her educational, living or recreational arrangements where FCT is practiced. Most agencies have existing procedures for setting and reviewing individuals’ goals and programs. It is strongly suggested that FCT records should be summarized and submitted for consideration at such reviews. (Remington-Gurney, 2009)

Naturally, similar data should be kept and regularly reviewed by professionals who use FCT in clinical practice. As Lof notes in relation to speech pathology practice across the board:

Ethical practice dictates that speech-language pathologists practice PBE [Practice Based Evidence] by constantly evaluating treatment effectiveness (Lof, 2011, p193).

Given the standard of most experimental data pertaining to FC, practice-based evidence is clearly a crucial adjunct to the evidence base.

3.5 Science Based practice

In his 2010 keynote address to the SPA national conference, Lof observed that:

One of the frequently stated drawbacks of [evidence-based practice in the field of Speech-Language Pathology] is that many of the treatments used clinically do not have peer-reviewed, empirically-based studies supporting their efficacy/efficiency This being the case, what we do have are well-established theories and principles that have been rigorously studied scientifically. ... If there is a scarcity of data on a specific topic, there probably are well established and tested theories that can help direct clinical practice. (Lof, 2011, p194)

On this basis, Lof modified the usual definition of EBP to embrace “*Science Based Practice ... the use of scientific thinking and procedures/methods, and interpretation of theories and models when making clinical decisions*” (Lof, 2011, p194).

In the absence of quality research specifically targeting FC users, research on overlapping populations - including research on sensory and movement differences - informs practitioners who work with clients who use FC.

The ability to pass messages relies on considerably more than an ability to communicate. It also demands cognitive and processing skills which, according to research undertaken since the 1990s, may not develop along typical pathways in individuals who have severe sensory and movement disorders. This is not to suggest that affected individuals are cognitively impaired, merely that they may have difficulty in tasks that are not directed by their own interests, including confrontational testing or message passing.

Research supporting this position has not focused directly on FC users, but on the overlapping population of individuals with autism. For this reason it must be approached cautiously: seen as providing “*well established and tested theories that can help direct clinical practice*” rather than direct evidence that confrontational testing or message passing is not an appropriate test of FC.

Please see Appendix C for a discussion of some of this research.

The lack of research directly focused on FC users may reflect the acknowledged difficulty of studying cognitive function in individuals who have complex communication needs. Such barriers seem insurmountable if “think aloud” protocols cannot be used to monitor cognitive function because researchers do not accept subjects’ communication as genuine.

The major barrier to research, however, is likely to be the barrage of vitriol hurled, via both professional and popular media, at any researcher who dares to show an interest in FC. This bigotry must be put aside before any progress can be made.

3.6 The status of “expert” opinion.

Mazerole and Legosz (2012) state that:

The accepted and stringent process of peer review, a cornerstone of scientific integrity, is one way of ensuring that the research methodologies and results are critically appraised according to [the hierarchy of research evidence] (Mazerole and Legosz, 2012, page 39)

Please see Section 1.1 regarding Kuhn's model of scientific enquiry, which suggests that traditional methods –what Kuhn calls “*normal science*” - are designed to maintain the *status quo* (Kuhn, 1962). As “experts” act as gate-keepers in research organisations and peer-reviewed journals, it is difficult to challenge the “received wisdom”.

This situation is not consistent with EBP, which:

... intentionally deemphasizes the role of expert authority and instead promotes a transparent, rational decision-making process that can be taught, refined, and applied by all clinicians (Satterfield *et al*, 2009, p371).

The NHMRC hierarchy of evidence (2000b, page 10) explicitly states that:

Current levels of evidence exclude expert opinion and consensus from an expert committee as they do not arise directly from scientific investigation (Mazerole and Legosz, 2012, page 35).

On the other hand, the hierarchy developed by the Oxford Centre for Evidence-based Medicine (2001), used to weight external research in Gillam and Gillam's model of EBP (see Section 2.3), does include “expert opinion”:

The lowest level of external evidence (Level 5) includes expert committee reports, conference proceedings, and/or opinions of respected authorities ... because the therapy recommendations are not based on objective data. Clinicians should be cautious about implementing therapy suggestions from experts unless those suggestions are based on well-designed studies or systematic reviews of high-level evidence. (Gillam and Gillam, 2006, page 308).

This low weighting for expert opinion should not be taken to imply that Gillam and Gillam consider expertise irrelevant. It is important to recognize that the Oxford hierarchy relates only to external evidence. Thus, although external “expert opinion” is ranked (along with recommendations from respected colleagues) at Level 5, practitioners' own expertise in the form of prior knowledge and skills is ranked at Level 2, suggesting that practitioners should have as much faith in their own knowledge and skills as they have in non-randomized studies, multiple base-line studies, and systematic reviews of such studies (subject to critical evaluation of the quality of the research). (Please see Table One in Section 2.3 regarding Gillam and Gillam's model.

Given the low or non-existent status of expert opinion in the hierarchies of evidence they have cited, is very surprising to find that the Queensland reviewers, Mazerole and Legosz, admit to being:

...swayed by the advice of experts who have studied these fields in great detail and in some cases, are leaders in both research and practice in these fields (Mazerole and Legosz, 2012, p65).

They advise that they relied on expert opinion because “[t]he time frame and [Terms of Reference] for this review limited our capacity to examine the research evidence ...” (Mazerole and Legosz, 2012, p65).

Mazerole and Legosz (2012) also gave weight to various position and policy papers. Gillam and Gillam include such “*opinions of respected authorities*” at the lowest level of external evidence. The danger in accepting “authority” rather than re-examining the research evidence is that errors in interpretation can, all too easily, be replicated.

4 Practitioner Expertise

4.1 The role of practitioner expertise in EBP

Gillam and Gillam (2006) suggests a model for EBP decision-making in a speech pathology context. A table showing their weighting scale for internal and external evidence can be found in Section 2.3. The authors state:

We do not believe that any clinician-agency factors should weigh as strongly as external evidence from RCTs, systematic reviews of RCTs, or a parent's strong cultural beliefs. But we do place a high value on prior knowledge and skills. Therefore, we placed education, the highest clinician-agency factor, at Level 2. Many clinicians are highly competent at implementing treatments that they have studied carefully, that they learned in graduate school, or that have been demonstrated to them by master clinicians. That is why clinicians should consider their own skills when they weigh treatment alternatives (Gillam and Gillam, 2006, p309)

Gillam and Gillam's model encourages practitioners to trust their own prior knowledge and skills, ranking these "internal factors" at Level 2 - equivalent to external evidence consisting of good quality non-randomised studies, multiple base-line studies, and systematic reviews of these (Gillam and Gillam, 2006). Note that Level 2 is the highest level of study available in FC (or, indeed, AAC) research – there are no randomly controlled trials. However, as the model demands that studies should not only be ranked but also critically evaluated, the poor quality of most "Level 2" studies leaves clinical experience and expertise more important than most existing research in the field. Further, as noted in Section 3.4, clinician-generated outcome data for clients is ranked at Levels 3 and 4 – comparable to much external evidence (research) and above expert opinion.

4.2 The elements of clinical expertise

As noted in Section 2.1.2, the American Psychological Association (APA) adopted a new approach to the question of integrating research and practice in 2005, releasing a model for Evidence-Based Practice in Psychology (EBPP). This model deepened the examination of clinical expertise. It noted that:

Clinical expertise is essential for identifying and integrating the best research evidence with clinical data (e.g. information obtained about the patient over the course of treatment) in the context of patient characteristics and preferences to deliver services that have the highest probability of achieving the goals of therapy (Levant, 2005, pp9-10).

The individual therapist has a substantial impact on outcomes, both in clinical trials and in practice settings The fact that treatment outcomes are systematically related to the provider of the treatment (above and beyond the type of treatment) provides strong evidence for the importance of understanding expertise in clinical practice as a way of enhancing patient outcomes (Levant, 2005, p10).

The Queensland review quotes a departmental Speech Language Pathologist as follows:

FC is a complex clinical area that cannot be judged without personal learning and application (submission, departmental SLP, quoted by Mazerole and Legosz, 2012, p62).

This statement reflects the need for clinicians to be flexible and responsive to their client, rather than focussed on highly prescriptive procedures and frequency counts. This is consistent with APA's advice:

Research suggests that sensitivity and flexibility in administering therapeutic interventions produces better outcomes than rigid application of manuals or principles Reviews of research on biases and heuristics in clinical judgement suggest procedures that clinicians might employ to minimise those biases... . Because of the importance of theoretical alliance to outcome ... , an understanding of the personal attributes and interventions of therapists that strengthen the alliance is essential for maximising the quality of patient care ... (Levant, 2005, p14)

The emphasis on personal judgement and flexibility in the quotes from the departmental SPA and from APA appear to be in contrast with the following quote regarding the Picture Exchange Communication System – a structured communication training system from the behavioural science tradition:

“PECS is a complex implementation system involving an array of teaching techniques derived from the field of applied behaviour analysis (Bondy and Frost, 1994) and as such, its relative complexity ‘sets the occasion for procedural variations, both intended and unintended’” (Bondy and Frost, 1994, cited in Mazerole and Legosz, 2012, p).

“[I]t is critical for investigators who are validating PECS to demonstrate fidelity with the teaching procedures outlined within Phases I through VI ... ” (Mazerole and Legosz, 2012, p90.)

Flexibility informed by clinical experience is stressed in the quotes from the departmental SPA and from APA; compliance with set procedures in reference to PECS. This helps to demonstrate the point that, if external authority is always seen as vastly superior to internal evidence, AAC professionals might just as well be replaced by technicians who can deliver AAC systems with a focus on “integrity” of the system rather than on how well it fits a client's needs, and what adjustments may need to be made to improve the fit.

4.3 Resources as a factor in decision-making

As noted in Section 2.3, SPA's Clinical Guideline for Augmentative and Alternative Communication (AAC) refers readers to the Transdisciplinary Model of Evidence Based Practice, (Satterfield, et al., 2009). In that model, the circle that had referred to “clinical expertise” in earlier models now refers to “resources, including practitioner's expertise” (Satterfield et al, 2009, p382).

The model does not provide explicit instruction regarding resolution of conflict between an agency's policies/ financial resources and clinician's expertise. Agency employees are clearly bound by their employer's policies and budgets. Perhaps the weighting suggested by Gillam and Gillam is intended to signal to agencies that, as much as

possible, their policies and budgets should be shaped by the professional practice and decision-making of the clinicians they employ (see Section 2.3).

SPA (2010), in discussing the Gillam and Gillam model, refers to an “*extra step*” which “*addresses the importance of an intervention being effective and economical*” (SPA, 2010, p5). Similarly, the NHMRC lists “*the availability of resources*” as one element of good decision making (NHMRC, 1999, p1).

These statements potentially conflict with ASHA’s *Position Statement on Access to Communication Services and Supports: Concerns Regarding the Application of Restrictive “Eligibility” Policies*. The Position Statement lists “*lack of adequate funds or other resources*” as one of the criteria that should **not** preclude consideration of individual needs (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2003).

None-the-less, the Queensland experience has demonstrated the devastating effect introduction of AAC strategies without adequate support may have. For example:
FC is an AAC and therefore susceptible to the same factors that influence outcomes in conventional AAC programs such as staff training needs, staff turnover lack of resources for communication opportunities and low prioritisation of the consumer’s right to communicate (Remington Gurnery, 1996, p6, quoted in Mazerole and Legosz, 2012, p112).

The Queensland review notes:

Beukelman and Mirenda (1998...) discussed several possible barriers to communication, including those related to policies, practices, attitudes, knowledge and skills. It is important therefore to not only identify the barriers and facilitators for AACs but also to design appropriate interventions and develop relevant policies to address them (Mazerole and Legosz, 2012, p.100).

The Queensland reviewers recognised the importance of efforts to address barriers to the use of AAC throughout the Department. One submission to the review by a staff member identified the following:

... challenges to ongoing and successful communication support in Disability Services, particularly accommodation support settings include:

- *Staff turnover – in both professional and support worker cohorts*
- *Lack of consistent communication partners and family members around individuals to champion communication progress*
- *Limited communication opportunities – particularly for adults who share a home with up to 3 or 4 other adults who also have communication challenges and who have one support worker on shift at a time.*
- *Lack of access to or lack of use of technology (high tech communication systems) in daily life* (Mazerole and Legosz, 2012, p.101-2).

5 Client characteristics, state, needs, values and preferences

In the Transdisciplinary Model of Evidence Based Practice (Satterfield, et al., 2009) the circle that had referred to “patient’s preferences” in earlier models becomes “*client’s/ population’s characteristics, state, needs, values and preferences*” (Satterfield et al, 2009, p382).

This is an important change. To illustrate, the definition of EBP that was used in the Queensland review was:

... ‘the integration of best and current research evidence with clinical/educational expertise and relevant stakeholder perspectives, in order to facilitate decisions about assessment and intervention that are deemed effective and efficient for a given direct stakeholder (Schlosser & Raghavendra, 2004, p.3, quoted in Mazerole and Legosz, 2012, p.47)

One author of this definition notes:

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)

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 individuals’ attitudes at the expense of their physical, sensory, neurological medical or other differences that may contribute to their complex communication needs. The need for assessment and accommodation of these highly individual differences is not overlooked by the Queensland reviewers, who observe that:

Evaluating a user’s abilities and requirements for AAC includes assessing the individual’s motor, visual, cognitive, language and communication strengths and weaknesses. It requires input from family members as well as the professional team assigned to work with the individual (Mazerole and Legosz, 2012, p80).

In 2005, the American Psychological Association (APA) releasing a model for Evidence-based practice in psychology (EBPP) – Please see Section 2.1.2. This has contributed significantly to the understanding of the role of patient characteristics as potential modifiers of outcome:

Normative data on “what works for whom” ... provide essential guides to effective practice. Nevertheless, psychological services are most likely to be effective when responsive to the patient’s specific problems, strengths, personality, sociocultural context and preferences Psychology’s long history of studying individual differences and developmental change, and its growing empirical literature related to human diversity ... place it in a strong position to

identify effective ways of integrating research and clinical expertise with an understanding of patient characteristics essential to EBPP ... (Levant, 2005, p14-15).

The APA statement lists patient related variables that may influence outcomes, including functional status; readiness to change; level of social support; variations in presenting problems or disorders; etiology; concurrent symptoms syndromes or behaviour; chronological age; developmental status; developmental history; life stage; sociocultural and familial factors; current environmental context; stressors; social factors such as discrimination or health care disparities; and personal preferences, values, goals, beliefs, worldviews, and treatment expectations (Levant, 2005). Importantly:

Psychologists must attend to the individual person to make the complex choices necessary to conceptualise, prioritise, and treat multiple symptoms (Levant, 2005, p16).

(Please see my comments in Appendix B, Section B3, regarding inadequate attention to the individual characteristics of subjects selected for group-based FC experiments.)

6 Conclusion

Most current academic, professional, and government comment about FC appears calculated simply to shut down debate.

This impacts one of the most vulnerable groups in society – individuals with literally no voice whose communication needs have not been met through conventional AAC support.

This in turn impacts families, schools, post-school programs, and society in general.

The terms of reference for this Inquiry include “*evidence of the social and economic cost of failing to treat communication ... disorders*”.

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.

Appendix A Movement Disorder

A.1 Attitudes in the 1990s

During the 1990s, observations that were suggestive to some of movement disorder were interpreted by many as prompt dependence; lack of motivation; lack of knowledge or understanding; or problems with memory and/or attention. (e.g. Green and Shane, 1994)

The generally held belief was that:

“... controlled neurological or neuropsychological research does not implicate developmental dyspraxia as a cardinal feature of autism or more severe forms of mental retardation, and there is evidence to the contrary”. (Jacobsen, Mulick and Schwartz, 1995)

This belief underlies the paradigmatic statement:

[T]he everyday facility with which people with autism or mental retardation use a language (e.g., spoken, written, or pictorial) is an accurate depiction of their ability to do so ... This standpoint is firmly grounded in an immense psychological literature in cognitive development, social development, and both general cognitive and social problem solving by children and adolescents That there is a strong presumptive relationship, in general, between overt production and actual ability is a cornerstone of psychological assessment methodology, statistics, and psychometrics.” (Jacobsen, Mulick and Schwartz 1995, p757)

Perhaps this blinkered approach was unsurprising. In 1995 little was known about developmental dyspraxia - despite the fact that it had been discussed in research literature under a variety of names for nearly 100 years (Dewey, 1995). The difficulty may have been that dyspraxia was largely the province of physical therapists, not psychologists, neurologists or neuropsychologists. Communication between the “silos” was, and continues to be, a challenge.

There have been considerable advances in understanding since the mid 1990s – (see for example Vaivre-Douret, Lalanne, Ingster-Moati, Boddaert, Cabrol, Dufier, Golsé, Falissard, 2011). It seems that developmental dyspraxia – or the encompassing diagnosis of “developmental coordination disorder” - is now widely accepted as a genuine condition that is considerably more prevalent than previously believed.

In the 1990s Australian researcher, Prof. Alan Hudson observed that:

“ ... individuals placed on facilitated communication rarely, if ever, have apraxia diagnosed by an appropriately qualified professional such as a neurologist or neuropsychologist. (Hudson, 1995, p.223)

Vaivre-Douret *et al.* (2011) suggest that assessment of children with “developmental coordination disorder” should integrate investigations of neuromuscular tone; visual motor perceptual versus visual perceptual tasks; neurovisual tasks; coordination, praxia, laterality, gnosis, and body integration (p638). Should such detailed assessments be required before an individual can be accepted as a candidate for FC? It seems likely that severe communication impairment may make such assessment extremely difficult, particularly in the absence of an established communication strategy. Assessments such

as these have not, to my knowledge, been part of the assessments Prof. Hudson has recently been involved with in Queensland.

FC was developed as a practical strategy for individuals “*whose communication could not be put on hold while they undertook a lengthy occupational therapy program*” (Crossley and Chadwick, 2000). FC instructor/ assessors are trained to identify difficulty with initiation; stopping; sequencing; continuing; switching; and combining motor action. (Remington-Gurney, 2009) While more detailed assessment may certainly be of value in understanding the needs of the individual and which interventions may help them, there appears to be considerable value in “just getting on with it”.

A.2 Recent Reviews and response

In 1995, statements such as those quoted above from Jacobsen, Mulick and Schwartz (1995) were frustrating but, as discussed, perhaps understandable due to the lack of communication between professional “silos”. It is, however, quite shocking to read similar statements in contemporary reviews:

To date, there is no substantive evidence to support theory argued to underpin FC that the people who use the method have an underlying movement disorder that warrants facilitation (SPA, 2012, p.30)

The research team was ... advised by three ... academic/practitioner experts in autism that the evidence regarding movement disorders and autism is currently weak and that it cannot yet support or explain the use of FC with autistic people (Mazerole and Legosz, 2012, p65).

On 4 January 2014, a “Google Scholar” search using the terms “autism” plus “movement disorder” returned “about 5,160” results. A similar search using the terms “autism” plus “dyspraxia” returned “about 5,620” results, and one replacing “dyspraxia” with “apraxia” returned “about 6,830” results. It is regrettable that the review team has taken the following approach to exploring this issue:

The time frame and TOR [Terms of Reference] for this review limited our capacity to examine the research evidence regarding movement disorders ... in any detail, but we were swayed by the advice of experts who have studied these fields in great detail and in some cases, are leaders in both research and practice in these fields (Mazerole and Legosz, 2012, p65).

I am not aware of published research addressing movement differences specifically in the FC population. As discussed in Section 3.5, under those circumstances “evidence based practice” refers the practitioner to research undertaken in overlapping populations. For comments on research into movement and sensory differences in autism, and the ways in which this research may support the use of FC, please see Appendix C.

A.3 What the research says

In a 2008 paper, Professor Pat Mirenda stated her position as follows:

I identify firmly with a positivist behavior analytic tradition that embraces the scientific method; thus based on the research evidence, my reading of the early FC literature is that most of the participants in those studies were influenced by

facilitators – whether consciously or unconsciously – as they typed with physical support” (Mirenda, 2008, p228)

I have included this statement to demonstrate that Professor Mirenda is, by no means, an apologist for FC.

The following is a list of studies of movement differences in autism, cited by Mirenda (2008):

- Kanner (1943) and Asperger (1944) described impairments of either voluntary or involuntary movement in their case studies.
- Provost, Lopez, and Heimerl (2007) found that none of their sample of 19 children with ASD had gross or fine motor skills in the normal/average range.
- Dyck, Piek, Hay, and Hallmayer (2007) reported a relationship between motor coordination scores and autism severity in a sample of 29 children with ASD and suggested that “*processes underlying motor coordination have been underestimated in explaining [ASD] symptoms*” (p. 258).
- Gernsbacher, Sauer, Geye, Schweigert, and Goldsmith (2008) found that early oral- and manual-motor skills distinguish children with ASD from typically developing children; and also distinguish among children with ASD whose current speech is minimally, moderately, and highly fluent.
- Dawson & Watling (2000) provided a review of several well-designed studies demonstrating significant praxis deficits in addition to both gross and fine motor impairments in individuals with ASD.
- Ming, Brimacombe, and Wagner (2007) found, in a sample of 154 children with ASD, that 41% of children 2–6 year olds and 27% of 7–18 year olds showed clear evidence of oral motor and/or hand muscle apraxia.
- Imitation skills that require either oral-facial praxis (e.g., sticking out the tongue, making a happy or sad face) or copying body movements that do not involve the use of objects are especially difficult for individuals with ASD and may differentiate them from individuals with other developmental disabilities (Adams, 1998; DeMyer, Alpern et al., 1972; Page & Boucher, 1998; Rogers, Bennetto, McEvoy, & Pennington, 1997; Stone, Ousley, & Littleford, 1997).
- Baranek et al., 2005 examined the prevalence and specificity of involuntary movement impairments. Involuntary movements in individuals with ASD include tics, akinesia, dyskinesia, akathisia, bradykinesia, and gait or posture abnormalities.
- There is evidence that tics, dyskinesia, and akathisia are all associated with repetitive stereotypic behaviors such as body rocking, repetitive self-injurious behavior, and compulsive behavior (Bodfish, Symons, Parker, & Lewis, 2000).
- However, while a number of studies have reported involuntary movement patterns in at least some individuals with ASD, it is not clear whether these patterns are specific to ASD. One exception was a recent comparative study that provided evidence of significantly reduced postural stability in individuals with autism (ages 5-52), compared to matched controls without disability (Minshew, Sung, Jones, & Furman, 2004).
- Hardan, Kilpatrick, Keshavan, & Minshew, 2003; Minshew & Williams, 2007 are examples of other papers showing that motor impairments are much more common than previously thought and may also be associated with autism symptoms.
- Minshew et al. (2004) noted the significance of:

*... associated symptoms that are not part of [the current] diagnostic constellation but nonetheless appear to be neurologically and clinically important elements of this syndrome. Abnormalities of motor coordination, posture, and gait are among these. Numerous studies have documented clumsiness and gross and fine motor apraxia, **which are now considered integral aspects of autism** (Minshew et al, 2004, p2056, cited in Mirenda, 2008, p222-223, emphasis added by Mirenda.)*

In 2012 the following question was asked during the on-line conference “Autism 2012” (<http://www.awares.org/conferences/default.asp>):

I very commonly hear professionals saying that there is no evidence that there is a high incidence of dyspraxia in autism, which always astounds me - because understanding dyspraxia has been the key to understanding my son. Can you comment on whether this question is still undecided in scientific circles?

Leading autism researcher Manuel Casanova, Professor of Anatomical Sciences and Neurobiology at the University of Louisville, answered: “*I would categorically state that dyspraxia is in autism ...*” Significantly, he observed that: “*Motor abnormalities in autism bear the characteristics of precedence and universality that characterize a core symptom*” (Casanova, November 2012).

He added further extended comment and an extensive list of references Those not already mentioned above include:

- Wing (1981); Burgoine and Wing (1983) proposed that ill-coordinated movements and odd posture is a central feature of Asperger Syndrome.
- Ornitz and associates (1977) noted that, by 6 months of age, autistic children have noticeable delays in attaining their motor milestones. The magnitude of the delay increases during the second half of their first year of life.
- The presence of delayed motor skills at 2 years of age is the clearest distinguishing factor for children who continue meeting diagnostic criteria for autism spectrum disorders (ASD) at four years of age (Sutera, et al. 2007).
- A study (n=15) using the locomotor and object control tasks of the Test of Gross Motor Development (TGMD) in autistic subjects revealed that all patients had below average to very poor locomotor skills and 12 out of 15 patients were similarly impaired in regards to object control skills (Berkeley et al., 2001).
- A study of dyspraxia in autism concluded that praxis in children with autism is strongly correlated with the social, communicative, and behavioural impairments that define the disorder, suggesting that dyspraxia may be a core feature of autism or a marker of the neurological abnormalities underlying the disorder (Dziuk et al., 2007, page 734).
- This deficit is specific to autism when compared to other neurodevelopmental disabilities, i.e. ADHD (MacNeil and Mostofsky, 2012).
- The neurological basis of dyspraxia is unknown. Subjects with ASD do worse than controls on a modified Romberg test, tandem gait and in repetitive finger-thumb apposition while performing satisfactorily in tasks of visual-motor integration. It has been estimated that 80% of subjects with autism display "motor dyspraxia," or clumsiness (Weimer et al., 2001).
- The pattern of symptoms suggests the presence of an underlying proprioceptive deficit and eliminates a vestibular abnormality in these patients. In general, when attempting localization, the genesis of proprioceptive deficits is usually attributed to a polyneuropathy (e.g. diabetic), dorsal column lesion, or cerebral cortical

abnormality. Neuropathological studies of apraxic/dyspraxic patients in idiopathic, secondary and progressive cases have usually emphasized cortical disturbances, e.g., corticobasal degeneration, Alzheimer's disease, Pick's disease, and stroke (Kawamura and Mochizuki, 1999).

- The emphasis in cortical deficits is instilled in one of the classifications for apraxia, which similar to aphasias, is categorized into motor, sensory, and conduction forms (Rowland and Pedley, 2010).

Another leading researcher, Dr Karl Reichelt from the University of Oslo, responded as follows to Professor Casanova's comments:

Apraxia is a symptom seen in some of the autism spectrum and of greatly varying degree. However, it is not found in all the children within autism spectrum and this is as we see the case for most symptoms in this disorder. The degree to which the same chemical changes in the brain affects different persons depends on the constitution of that person. In any one synapse for instance the fate of a released transmitter depends on reuptake mechanism, pre-synaptic receptors and post synaptic receptors as well as receptors on the supporting cells (glia). If the transmitter is peptidic or acetyl choline also on the speed of hydrolysis. It is therefore not very strange that a spectrum of symptoms varies from one child to the next. This is why it is often difficult to make a diagnosis because of the individuality of the symptom profile and the degree or intensity of each symptom. In our present state of enormous ignorance the correct statement would probably be that some of the autism spectrum children show apraxia. It is not unreasonable that chemical deviations would also affect motor neurons but to a varying degree. Peculiar gait is also frequent ... but again not shown by all.

In a previous AWARES conference, I had asked pioneering autism researcher Uta Frith (in relation to a different question):

As a parent, I find it very difficult to understand how there can be so much rigorous, "peer reviewed" - but apparently conflicting research. How are we to decide which explanation to follow? It does seem important for choice of intervention, doesn't it?

Professor Frith replied:

It is the nature of research into such complex things as mind and brain that it is slow and conflicting. This is because we do not yet have a good theory of how the brain works at all. Therefore, at present any individual result has to be backed up by a replication and has to be consistent with other studies before we can even think of application in practice. Unfortunately, this means there is precious little knowledge that is ready to be applied as backed by a proper evidence base. In the meantime all we can do is experiment with different ideas and different methods that link up with current research, but this has to be understood as 'experimental'. In fact, it is sometimes from actual practice that an idea gets taken up by the researchers, and then turns into the next theory. It is very frustrating that despite the large amount of research, there is still so little to hang on to. However, this is what to expect of the stage of research we are in. Physics research since Archimedes had hundreds if not thousands of years to develop, psychology only about one hundred years. (Frith, October 2012).

When a giant of autism research such as Professor Frith is able to embrace the concept that research into autism is “a work in progress”, it is surely not too much to ask the same of administrators and practitioners.

A.4 Movement demands in AAC other than FC

I will confine my comments to PECS, however please note that the same issues may arise in respect of other AAC strategies.

Mazerole and Legosz cite peer reviewed comment which asserts that PECS avoids access and cognitive issues:

Unlike other AAC systems, PECS is unique in that it does not require prerequisite skills, such as pointing, labelling or matching, but rather teaches individuals to request preferred items, which is a functional skill maintained by consequent access to preferred reinforcers (Lancioni, O’Reilly, Cuvo, Singh, Sigafos, and Didden, 2007, referenced in Mazerole and Legosz, 2012, p82).

The reviewers also quote Professor Alan Hudson’s statement regarding access:

The technology of today is so well developed that a person only has to be able to control one response (e.g. blink, blow in a straw, push a button) to be able to truly independently communicate (Professor Alan Hudson, submission to review, 2011 p.4, quoted in Mazerole and Legosz, 2012, p93.)

Both of these statements indicate a remarkable lack of understanding of ways in which movement differences may interfere with communication.

While individuals may be able to “*blink, blow in a straw, [or] push a button*”, they may have difficulties initiating the movement in a timely fashion when needed, or inhibiting it when they have made their point. They may have difficulty sequencing or sustaining their movement as required to complete a message, or disengaging from other stimuli in order to switch their attention to the communication task. They may have difficulty combining movements, or combining a focus on the demands of controlled movement with other demands of a communicative task such as attention to their communication partner, their environment, or their own inner states.

These are the types of movement disturbance that have been identified in FC users, including those with ASD (Remington-Gurney, 2009).

In the absence of “*initial trials ... to determine whether or not the individual has the necessary sensory and motor skills to use the method in question*” (Dowden and Cook, 2002, quoted in Mazerole and Legosz, 2012, p.80), and in the absence of ongoing monitoring and adjustment of programs to match the user’s requirements over time, a “one size fits all” approach is likely.

Such an approach may be behind such comments as “*PECS ha[s] emerged as the AAC intervention of choice for individuals with ASD*” (Tincani and Devis, 2010, cited in Mazerole and Legosz, 2012, p.82) and:

PECS is the most popular intervention for children with autism and related disabilities. For example, Stahmer, Collings & Palinkas (2005) found that 95 per cent of children with autism in California community early intervention programs

received PECS, more than any other intervention method (Mazerole and Legosz, 2012, p.82).

Neither of these statements make it clear whether the decision to offer PECS has been based on an assessment of each individual's need, or on a top-down expectation that PECS should be the only system offered. This is of concern given that:

... general statements about successful or unsuccessful interventions are of little value for guiding the selection of AAC approaches for a specific person (Wendt, 2009, p108, quoted in Mazerole and Legosz, 2012, p.84).

Appendix B: Experimental design

B.1 Introduction

According to Lof (2011), clinical practice should be based on evidence from experiments which test “*the impact of an intervention under highly regulated circumstances, controlling for confounding variables that can negatively influence the findings*” (p193). However, experiments must be carefully designed if they are to achieve this goal. Poor design may produce “results” that are mere artefacts of design flaws.

Green and Shane (1994, p.163) observed that:

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.

There was certainly consistency in the results obtained from “controlled” experimental studies of FC conducted during the 1990s and, to a lesser extent, the 2000s. There was also, however, an unfortunate consistency in the design of experiments, with heavy emphasis on confrontational testing/ message passing in highly contrived circumstances. As such, it cannot be said that the experiments were “*each using somewhat different methods and flawed in different ways*”.

Mostert (2001, p311) reported that:

... studies incorporating control procedures find very little to no support for the efficacy of FC, studies employing fewer control procedures produce mixed results, and studies ignoring control procedures almost universally find FC to be effective.

Mostert, along with many other commentators, interpreted such results as proof that FC does not work. They strongly imply that, when the results of “*studies incorporating control procedures*” were so at odds with “*studies ignoring control procedures*” – that is, for example, observational studies in natural settings – the results of the former have clear superiority over those of the latter.

Yet, the design of most controlled experiments to date has been inadequate to eliminate the obvious rival explanation: that the control procedures themselves may have interfered with the phenomenon being studied, rendering the results invalid.

Nor did most experimental designs allow any conclusions to be drawn regarding individual FC users’ capacity for self-motivated communication in supportive, naturalistic circumstances.

In fact, the only conclusions that might be drawn from these experiments are that confrontational testing and message passing may be difficult for FC users, and that facilitators may, under experimental conditions, influence communication. Neither of these conclusions would be difficult for supporters of FC to accept.

It should be noted, however, that in many studies the procedure implemented and subjected to investigation bore only superficial resemblance to FC. It is not possible to draw any conclusion at all about FC “best practice” from such studies.

Reports of individual studies - as opposed to review articles that merely collate “findings” - show that experiments were overwhelmingly based on demonstrably poor understandings of what FC is (and isn’t), with resulting poor practice. Many are also characterized by inappropriate selection of subjects; poor training delivered to FC users and facilitators; and intrusive “controls” highly likely to alter both the support needs of the subjects and the nature of support that can be provided.

Please note that limitations on time and on access to the literature have meant that I have only been able to review a handful of papers, however I hope that the comments I make based on this sample may be adequate to highlight potential pitfalls in other studies, so that members of the Committee may approach their reading with an awareness of some of the main issues.

B.2 Poor understanding of FC Practice/ Poor Facilitator Training

One of the problems faced by experimenters in the 1990s was the astoundingly haphazard spread of FC through North America, resulting in confusion over the nature of the strategy and over what was being claimed by its proponents. As observed by Green and Shane it:

“ ... was placed in immediate and widespread use by large numbers of individuals ranging from high-school educated aides to professionals, with no monitoring, supervision, safeguards, or objective evaluation. Little or no training was required to use the method. (Green and Shane, 1994, p166)

Similarly, Simpson and Myles (1995) note:

“ ...the procedure has the likely potential of being used in an inconsistent and potentially wanton fashion until it is better understood. In some instances facilitators have almost no training in facilitated communication; in other cases individuals are trained to use facilitated communication with only minimal regard for specified methodology; and users of facilitated communication routinely fail to follow consistent routines and guidelines. That most colleges and universities have been reluctant to train individuals to use facilitated communication until the procedure is better understood and shown to be efficacious only intensifies this problem.”

Most studies published in peer-reviewed journals are from North America and date from this period. In many, facilitators were minimally trained. Using Eberlin *et al* (1993) as an example, facilitators were given four hours training and intermittent on-the-job supervision by two of the paper’s authors who had “*attended workshops on FC*” (p.517). The authors acknowledge that insufficient training of facilitators may be a potential criticism of their study, particularly compared with training at “*Crossley’s DEAL Communication Centre in Australia*”, where “*facilitators must be closely supervised and trained for at least 6 months before they become independently competent at facilitation*” (p527). They none-the-less defend the approach to facilitator training taken in their study, on the basis of various contemporary quotes from Doug Biklen that appear to indicate that minimal facilitator training is adequate.

Even a superficial examination of controlled studies published in peer reviewed literature reveal poor understanding and application of facilitated communication training technique, undoubtedly reflecting this haphazard approach to training. Some examples are discussed below.

B.2.1 Focus on activities unlikely to motivate subjects or to alleviate communication frustration.

Almost all studies emphasized message passing, or closely related activities, in highly contrived circumstances. No conclusions may be drawn from such studies regarding individuals' capacity for self-motivated communication in supportive, naturalistic circumstances. In fact, self-motivated communication (described, for example, as "*extraneous thoughts*" in Crews, Sanders, Hensley, Johnson, Bonaventura, Rhodes & Garren, 1995) is likely to be scored "incorrect" in these studies.

This very significant flaw applies to the vast majority of controlled studies, but I will use Cabay (1994) as an example. In Cabay, two sets of twenty cards were shown to subjects for approximately 15 seconds each - ten blank and ten with fill-in or short answer questions. Questions were identical in both sets – only the order varied. The "facilitator aware" condition was delivered first, as attempts to deliver the "facilitator unaware" condition first had resulted in a number of subjects being uncooperative and thus excluded from the study.

Cabay provides an Appendix showing "Stimuli, Responses and Scoring Data for Subject 2" (p.525-6). The subject's initial response to the first question included the words "*childish*" and "*I don't know the question*", however facilitators were instructed "*to direct subjects to the task or clarify garbled responses*" (p521) and the subsequent answer to the first question was marked as correct. The response to the second question included the words "*I can't decide how to answer that question*", but again an answer considered correct was eventually given. By question 12, the subject had keyed "*I call it a day*", and at question 14 he keyed "*DONT WANT TO DO THIS NOW I AM GETTING TIRED*" – both scored "incorrect". At questions 18 and 19 he keyed, respectively, "*I AM TIRED AND I WANT TOP ST*" and "*I AM III NOT ENJOY*", but went on to give answers considered correct.

In the "facilitator unaware" condition, the subject "correctly" responded only five times, identifying a blank card in each case. (It is not clear whether this was a spelled response, or indicated some other way.) The "incorrect" responses were statements indicating increasing distress, including a verbal statement "*I'm so tired*" (question 3); "*GOING HEADING HOM*"; (question 6); "*I DON'T LIKE HAVING THE C CAMERA ON. IT MAKES ME NER VOUS. OK I WILL TRY HOPEFULLY I CAN IGNORE THE CAMERA*", (question 7); "*I AM NERVOS*" (question 9); "*IM E (gets up) HOM (gets up) HOME AND (gets up) SLEEP*" (question 11); "*HO MO MORE (gets up) GO MOW I HAVE TO GO TO STORE AFTER SCHOOL TO BUY A WATER GUN. I AM NOT HAVING A BNGO RAVLE TIMME*" (question 13). Beyond this responses become increasingly difficult to interpret. It appears that the session was terminated after question 17 (Cabay, 1994, pp. 525-6).

The "procedures" section of the paper indicates that questioning was to continue "*until the 20 cards were presented in each condition, or until the facilitator determined the*

subject was no longer cooperating” (p520). As subjects in most modern trials are advised they can stop at any time, it seems incomprehensible that this ordeal was not terminated at question 12 of the “facilitator aware” condition, in which the subject clearly indicated a desire to stop. Please see comments in Section B.4 below, which may explain why this was not done.

B.2.2 “Blind” and “double blind” conditions not allowing interactional support such as reducing the “level” of interaction.

Awareness of different “levels” of interaction was apparent in some reports - e.g. Eberlin *et al*, 1993, mentions that the “communication ladder” was included in facilitator training. However, the impression given in this report is that the purpose of the communication ladder was simply measurement of progress to higher levels of operation. There appeared to be no understanding that interactional support may be increased when needed by reducing the “level” of conversation – that is, by providing more context or offering the FC user a choice of two or three possible answers. This should have been a key element of facilitator training, reflecting “best practice”.

Appropriately trained facilitators would know to provide more transactional support when other factors (for example, environmental supports) are less than optimal. The highly contrived circumstances created by intrusive experimental controls (see Section B.5 below) are likely to reduce environmental support. However, under “blind” and “double blind” conditions, neither the context for communication, nor a range of possibly correct responses from which a choice might be made, is known. As a result, it is extremely difficult to increase transactional support.

No study appeared to be concerned about – or even aware of - this major limitation imposed on FC support by the experimental designs. For example, Cabay (1994) suggested that if subjects either did not respond, indicated anxiety, or were uncooperative, the prompt hierarchy should be “1. *Please try to answer the question*; 2. *Give it a try*; 3. *We’ll go on to the next question now*” (p520). This clearly bears no resemblance to the reduction in “level” of communication described in facilitator training.

Another difficulty under “blind” and “double-blind” conditions is that facilitators are not in a position to provide feedback after a participant has responded. This shift from what is likely to be the usual relaxed, reciprocal relationship with their facilitator under training conditions to a more confrontational, interrogation approach under test conditions can be extremely confusing. There are anecdotal reports of FC users making deliberately incorrect responses under test conditions in an effort to elicit a response from his facilitator.

B.2.3 Failure to use the strategy of “error prevention”

As Smith and Belcher (1993) note:

... trainers of facilitated communication recommend an error prevention procedure of helping the student to not make mistakes, by pulling the student's hand back from a clearly wrong selection. ... Since facilitators in this study could not distinguish between errors and random responding, subjects were not prevented from striking keys to which they pointed. (p 179).

The paper describes the first FC training session in which subjects were asked to type the letters of the alphabet as the facilitator named them. They were later asked to type the answers to simple questions such as “*What is your name?*”. Clearly under these circumstances the facilitator would know the expected response, and would be able to take action to prevent an error from occurring – at the same time gaining useful information about the subject’s movement and/or ability to comply with the request. Even when the response is not known, certain letter combinations do not appear in words, so facilitators would be able to identify at least some preventable errors. Providing physical support while a subject types random letters does not constitute Facilitated Communication Training.

Failure to use the strategy of errorless learning is explicit in Smith and Belcher, 1993, but also implied in many other studies through use of phrases such as “*random string of letters*”, e.g. Bomba, O’Donnell, Markowitz, & Holmes, 1996; Cabay, 1994. To quote Eberlin *et al* (1993) as an example:

... almost every subject commenced typing following the questions in the pretest and posttest. However their typed responses to questions were short strings of letters that were undecipherable, except in the rare case when a correct response was given (p.523).

B.2.4 FC not recognised as only one part of a multi-modal communication strategy.

Using Eberlin *et al* (1993) as an example:

Although many subjects continued to indicate their answers with established communicative modalities (e.g. speech), they were prompted to type their answers and only their typed answers were scored for correctness (p. 519)

Subject 1’s facilitator felt that his ability to type was equal to his expressive speech ability, but reported that this student did not like answering questions on the communicator, although he liked to play by typing words he chose himself. Our other typist, Subject 5, appeared to become irritated that he had to repeat himself by also typing his answer (p. 525).

These comments make it clear that neither experimenters nor facilitators were aware of the importance of encouraging all forms of communication. A similar lack of awareness was apparent in other studies, in which auditory screening of the facilitators blocked any verbal communication (e.g. Beck & Pirovano, 1996; Bebko *et al*, 1996; Bomba *et al*, 1996). Not accepting the participants’ “*established communicative modalities*” is inappropriate, disrespectful, and certainly not consistent with FC best practice.

Further, see Section B.3.3 regarding the importance of considering existing modes of communication when assessing the suitability of FC for particular individuals.

B.2.5 Over-focus on literacy.

Many studies inappropriately focused on literacy to the exclusion of other media such as objects and pictures. Examples include Bomba *et al* (1996); Cabay (1994); Crews *et al* (1995); Eberlin *et al* (1993); Hirshoren & Gregory (1995); and Montee, Miltenberger & Wittrock (1995). Eberlin *et al* (1993) goes so far as to suggest that: “*... guidelines state the facilitator must assume literacy skills ...*” (p508). This is clearly a misinterpretation

of the requirement that facilitators should assume competence, rather than operate from any pre-conception of an individual's communicative or intellectual capacity.

FC is an accessing strategy that may allow individuals to point for communication purposes. What they point to will depend on their own abilities and preferences, the circumstances under which they are communicating, and the skill of their facilitator in recognizing the most appropriate media. As such, choices offered may include objects, pictures, or symbols as well as words and letters.

As an aside, it is important to recognise the limitations of systems that offer limited vocabulary, tense, semantic and pragmatic markers, or repair strategies. While accepting that “[i]ndividuals who use AAC will be at different places on the continuum of literacy learning” (SPA, 2012, p26.), it must also be recognised that “*service delivery includes providing a system for the present (today) while planning for the system for the future (tomorrow) (Beukelman & Mirenda, 2005)*” (cited in SPA, 2012, p16). As noted in SPA's Clinical Guideline for AAC:

The development of literacy skills in both reading and writing is critical for all individuals, but it is especially important for those who use AAC with symbolic understanding (see Smith, 2003). The symbols provided in AAC systems may enable individuals with complex communication needs to communicate a wide variety of messages, however, the alphabet is the only symbol set that allows precise communication and unlimited message generation (Erickson & Clendon, 2009) (Speech Pathology Australia, 2012, p.25-6.)

For comparison, the early stages of the Picture Exchange Communication System (PECS) are based on pictures or symbols. As noted in the Queensland review,

... the utility of PECS in promoting more advanced communication skills, including tacts (i.e. expressive labels) and intraverbals (i.e. conversation) has not been established. ... [T]he majority of participants ... mastered only up to Phases I, II or III ... (Mazerole and Legosz, 2012, p.90)

B.2.6 Facilitator failure to encourage initiation.

E.g Beck and Pirovano (1996) note that – because facilitators were blocked from visual and auditory stimuli - the experimenter had to tap the facilitator to indicate “*when to begin facilitating the subject*” (p.503). That this represents an omission in the experimenter's understanding of FC, and in facilitator training, may be reflected in their comment that:

None of the subjects appeared to have made substantial gains toward independent communication through the use of FC but instead appeared to have learned to wait for someone else to support them before attempting a communicative response (Beck and Pirovano, 1996, p.510).

B.2.7 Lack of awareness of techniques for fading of physical support

Several studies mention that little or no fading had been achieved (e.g. Beck and Pirovano, 1996). This suggests that techniques for fading may not have been adequately dealt with in facilitator training. Alternatively, it may not have been understood that the time required for fading support will vary from individual to individual, depending on the complexity of their movement differences, and that very commonly the duration of the studies was too short to achieve significant fading.

B.2.8 Time limits

Some trials limited the time participants were exposed to visual stimuli (e.g. Bebkö, Perry and Bryson, 1996) or sought time-limited responses (e.g. Beck and Pirovano, 1996; Bomba *et al*, 1996; Eberlin *et al*, 1993). Time limits are likely to be inappropriate for a population characterized by motor planning difficulties, due to the motor planning demands of orienting to stimuli and of communicating a response.

B.2.9 An example of complete misrepresentation of the strategy

As already noted, quantitative research into FC generally displays an unfortunate consistency in the design of experiments, with heavy emphasis on confrontational testing and/or message passing in highly contrived circumstances. One of the few studies using an alternative experimental design, Wegner, Fuller and Sparrow (2003), has been described as follows:

Among the many empirical studies that have found FC to be useless, Wegner, Fuller and Sparrow (2003) ... provide perhaps the strongest case with high levels of confidence refuting claims that FC is an effective intervention and that communication is the function of the client and not the facilitator (Mostert, 2010, pp37-38).

It is extremely important to note that Wegner *et al* (2003) has not, in fact, been designed to establish whether FC is or is not “useless”. The assumption that FC is useless is fully incorporated into the experimental design. Under those circumstances, it can hardly be claimed as a “finding”.

In this study, participants cast in the role of “facilitators” were asked to place the index and middle finger of their right hand on two keys of a standard keyboard marked “yes” and “no”, while “communicators” placed the index and middle fingers of their left hand on top of them.

“Facilitators” heard questions through headphones. They were told:

*... Listen to the questions, but make no attempt to answer them yourself. You are trying to sense the communicator’s answers by paying attention to muscle movements in her (his) fingers. ... Please provide an answer to each question, even if you think you’re not feeling anything, because you may be tapping into something of which you are not aware (Wegner *et al* , 2003, p11).*

“Communicators” were, in fact, confederates who had been told to be “inert” and who – unknown to the “facilitator” - heard no questions through their headphones. In the presence of the “facilitator”, they were told:

*As you listen to the questions, clearly form the answer to each one in your mind, but make no attempt to press the keys physically. It is the facilitator’s job to sense which key you want to press” (Wegner *et al* , 2003, p11).*

Experiment five deviated even further from FC practice: there was no touch between “facilitator” and “communicator”, and the “facilitator” was told:

*You are trying to sense the communicator’s answers by empathizing with him or her (Wegner *et al* , 2003, p14).*

Clearly these experimental designs have nothing whatsoever in common with FC as it is practiced in Queensland (or anywhere else!). Not only do they bear no resemblance to

FC: the assumption of an inert “communicator” allows no exploration of a situation in which a communicator has something to say and is highly motivated to do so. It certainly allows no exploration of how touch may facilitate the movement of a communicator who has a movement disorder. The experiments are exclusively designed to expand on the authors’ assertion that FC is part of “*the family of phenomena known as motor automatisms*” (Wegner *et al*, 2003, p6). This assertion is not questioned, but is an assumption incorporated into the experimental design.

Although closer analysis of this study further highlights its limitations, it may provide some insight into the phenomenon of accidental facilitator influence in the context of simple tasks. As such, it may offer support for the suggestion that more open-ended, complex communication is less open to facilitator influence, and is therefore a more appropriate target for future research.

B.3 Selection of subjects

B.3.1 Initial evaluation of potential FC users

Queensland DCCS policy identifies potential FC candidates as individuals who:

... have CCN and a movement disorder that results in difficulty with the clear, unambiguous selection of nominated items from communication displays and ... have unsuccessfully used other communication methods (Mazerole and Legosz, 2012, p.178).

In Queensland - in both the public and the private sector - only practitioners trained to the level of “Instructor” are considered qualified to assess whether FCT may be an appropriate access strategy for a particular individual. Identification of movement disorder and disturbance, as well as evaluation of how well an individual’s existing communication strategies are meeting his or her needs, are central to such assessment.

Some studies (e.g. Cabay, 1994; Crews *et al*, 1995; Beck and Pirovano, 1996; Edelson, Rimland, Berger, & Billings, 1998) chose subjects who had already been using FC and who may, therefore, have undergone appropriate assessment. However there are few if any records of such assessment occurring, and no details of movement differences that may thus have been identified. These details would be recorded under “best practice” guidelines.

Other studies sought to introduce FC to groups of subjects who had not previously used the strategy, in an effort to monitor any emergence of new skills (e.g. Bebko *et al*, 1996; Bomba *et al*, 1996; Eberlin *et al*, 1993; Myles, Simpson & Smith, 1996b; Smith & Belcher, 1993.) These studies, almost universally, demonstrated inappropriate choice of subjects, poor facilitator training and FC practice, and unsurprisingly little or no benefit of FC under controlled conditions - although some do include anecdotal reports of successful communication under training conditions (e.g. Eberlin *et al*, 1993).

Bomba *et al* (1996) provides an example of the kind of pre-test that was administered to participants in lieu of appropriate assessment, “*to determine if any of the participants were “immediate responders” (i.e., able to use FC without prior training)*” (pp 48-49).

Participants in Bomba *et al* (1996) were chosen simply on the basis of a diagnosis of autism and “*significant deficits in adaptive behaviour across all developmental domains*” (p. 43). No assessment – or even mention – of possible movement differences was made.

A Cannon Communicator was introduced for the first time in the pre-test. No other displays or devices were provided.

Facilitators were screened from auditory input through headphones and from visual input by a physical barrier (thus rendering supportive feedback or rephrasing of questions – techniques that should have been emphasized in facilitator training - impossible).

In the pre-test, a range of set questions (of dubious suitability) was put. Questions not answered by typing on the keyboard were repeated after 30 seconds, and if still not answered after another 30 seconds were recorded as a non-response. This shows no awareness of the possible impact of movement disorder on response time.

The test ran for thirty to sixty minutes, compared to subsequent training sessions which ran for only five to twenty-five minutes “*depending on the participant’s resistance to the demands of the session*” (p. 51). It will come as no surprise that:

Participants frequently resisted facilitation and attempted to avoid the situation by pulling away from the facilitator or attempting to leave the area. When redirected to typing, several participants engaged in tantrumous (crying, vocalizing loudly) and aggressive (hitting, scratching, and kicking) behaviour (p.52).

The only surprise may be that one participant was able to answer two of the questions appropriately – by typing “y” to indicate that he wished to receive a food item. However, this was apparently well within his known range of abilities without facilitation.

Eberlin *et al* (1993) administered a similar pre-test. They reported that:

... after an initial exposure to FC no student demonstrated unexpected literacy or improved communicative ability. This finding stands in contrast to the uncontrolled case study reports claiming that individuals with autism often successfully communicate at unexpected levels during their first encounter with FC (p. 526).

It is difficult to express how significantly initial assessment by an appropriately trained clinician differs from the pre-tests described in these studies. Successful communication under the “controlled” conditions described above would be almost inconceivable – even for experienced FC users. The conditions would, almost inevitably, create a complete barrier for anyone who had not previously received FC training.

B.3.2 Movement difference

Introductory comments in some reports referred briefly to movement difference as a potentially significant factor, however no understanding of this was demonstrated in the recruitment of subjects. Rather, subjects were typically defined on the basis of primary diagnoses, mental age, adaptive or “aberrant” behaviours, unfacilitated expressive language abilities, etc. (e.g. Bebko *et al*, 1996; Beck & Pirovano, 1996; Bomba *et al*, 1996; Crews *et al*, 1995; Myles, Simpson & Smith, 1996b; Eberlin *et al*, 1993).

For example Bebko *et al* (1996) described FC as a method used with individuals who had “*developmental or motor disabilities*”, hypothesized to assist because the facilitator’s touch “*provides emotional support ... [and] enables the individual to overcome an assumed apraxia or dyskinesia*” (p20). Yet there is nothing in their paper to suggest that movement difference had been considered in any way when they were choosing their subjects, nor when they were analysing their data:

We looked for ... relationships between patterns of responding and student characteristics. However, nothing clear was found with regard to any of the various descriptor variables: age, gender, mental age, receptive or expressive language level, or diagnosis. (Bebko et al, 1996, p38).

Clearly movement difference was not considered.

Similarly, Bomba *et al* (1996) stated that:

The rationale for the use of this technique is that the physical support enables the individual to overcome assumed neuromotor difficulties and impaired volitional control which presumably restricts his or her own ability to communicate.

No further mention of movement (or “neuromotor”) difficulties is made in the paper, despite acknowledgment on the final page that individuals with autism are a highly heterogeneous group and that, if FC is shown to be effective for a sub-group, it will be important to identify the characteristics of that sub-group. Their closing paragraph notes variations in “*symptomatology, severity of the symptoms, cognitive functioning, and the presence of other general medical conditions such as seizures and sensory impairments*”, but makes no specific mention of movement difference or disturbance.

Crews *et al* (1995) also fails to demonstrate any understanding of this issue. Their paper dismisses potentially positive findings in one subject because “*the subject gave no behavioural indication (e.g., head nods) of which of his responses were the intended correct ones*” (p212). Although the paper notes that this subject could use some sounds and gestures, it does not indicate whether head nods were a reliable part of his repertoire – something that could certainly not be taken for granted in a population characterized by movement differences. (It was noted that the subject had cerebral palsy.)

Eberlin *et al* (1993) makes the interesting comment that:

FC was originally developed for individuals with cerebral palsy ..., who clearly had motoric difficulties and needed the assistance provided by FC or other augmentative communication systems. Of relevance to this article are more recent reports of surprising findings of advanced literacy skills with autistic individuals (p. 508).

Potential movement differences in the autistic population were clearly not considered by Eberlin *et al*, as evident from their criteria for inclusion in this study:

(a) a confirmed diagnosis of autism; (b) their speech therapist’s subjective impression that the person may be able to express more through FC than through their already existing communicative forms; (c) an absence of a history of property destruction (to avoid loss of equipment); and (d) availability for participation (Eberlin et al, 1993, p.510-511).

B.3.3 Comparison with existing communication strategies

Many studies appeared to have included subjects for whom FC provided no advantage over their other forms of communication. (For example Bebko *et al*, 1996; Bomba *et al*, 1996; Eberlin *et al* 1993, and Montee, Miltenberger & Wittrock, 1995).

Using Bebko *et al.* as an example, it is stated that subjects received an initial “6 weeks of FC”, followed up for a subset of participants “by 5 to 7 months of continued FC use, with the fading of physical supports, where possible” (p26). Subjects were selected for the additional period were those whose “facilitators’ anecdotal reports suggested potential success with FC, or for whom the data from the various designs did not present a consistent picture” (Bebko *et al*, 1996, p35-6). This seems to imply some success with use of FC in training conditions - presumably under naturalistic circumstances - however no details are reported. It is certainly difficult to imagine how FC training may have proceeded if there had not been more success under training conditions, as published results “imply that performance with FC was no better than the level of responding the students produced independently, even after up to 7 months use of FC” (p37). If this was the case under training conditions as well as test conditions, it is clear that this group of participants should not have been considered appropriate candidates for FC.

Similarly, Bomba *et al* (1996) record that, even under training conditions, subjects’ “communicative competence was significantly greater when they used their familiar modes of communication” (p. 52) The authors of this study did at least raise the question: “Were the students selected for participation in this study simply not appropriate for successful FC? (p54)”, however it is likely that we will never know, given the serious flaws in the way FC training was presented in this study.

Eberlin *et al* (1993) did record facilitator’s reports of “unexpected literacy skills” (p.524) under training conditions (as opposed to “controlled” conditions). The authors dismissed this as indicative of facilitator influence, but the experimental design was insufficient to control for alternative explanations, for example that the controls themselves significantly interfered with communication under “controlled conditions”. As such, the question of whether FC offered these participants any advantage over their established modes of communication remains open, despite the findings that: “Of 21 subjects 20 were less able to answer questions correctly at posttest than at their previously established communicative abilities (p.523)”

Beck and Pirivano (1996) further illustrate the limitations of comparing FC with existing communication strategies in the context of narrowly defined activities. In this study, data indicated that one subject may have benefited from FC when undertaking the Peabody Picture Vocabulary test, however she could perform equally as well independently “given appropriate stimuli” (p.509). That is, this subject’s independent performance given auditory stimuli was equivalent to her facilitated performance given visual stimuli (a raw score of 15 in both.) The authors conclude that “FC would therefore not be an appropriate procedure to use with this subject on this task (p.509)”, but seem to extrapolate from this to an implied conclusion that FC would offer the subject no advantage on any task.

This implication is a significant leap that cannot be supported by the data obtained. There is no record as to whether FC was made available to assist this individual with more complex or more self-selected communication, or in conditions when “appropriate

stimuli” was not available. Her independent performance with visual stimuli was given a raw score of 2, compared with 15 when facilitated. It is conceivable that FC may have allowed this individual to participate in less restricted settings where “stimuli” could not always be presented in the optimum manner. As noted in Appendix C and Appendix D, Section D.6, participation in a wide range of settings may help individuals overcome some of the cascading secondary effects of their more primary sensory and motor differences.

B.4 Attitude and anxiety

A common criticism of controlled investigations into FC is that subjects may become anxious or offended, thus altering their support needs under test conditions, or that negative attitudes of facilitators and researchers may influence outcomes (e.g. Biklen & Duchan, 1994). The latter issue may have been particularly relevant during the mid to late 1990s, when FC was extremely controversial in the general and academic media. This coincided with the bulk of quantitative studies being conducted.

Monitoring for attitude and anxiety - where this issue has been acknowledged at all - has relied on subjective, anecdotal reports of participants’ “appearance” – a notoriously difficult measure in a population characterized by movement disorder and non-verbal communication impairment. Examples of responses to this issue include the following:

“... maintenance of good rapport and trust was emphasized continuously throughout the training sessions. However, we were unaware of methods for measuring concepts such as rapport or trust with our clients who were mostly nonverbal. The assumption of adequate rapport was based on observations of the subjects behaviour during training and testing.” Eberlin et al, 1993, p527.

Proponents of FC might interpret the resistance seen in the early stages of this study as resistance to a "testing for competency" situation. However, anecdotal data make this explanation unlikely (Bomba et al, 1996, p53)

Unfortunately, no quantitative measures were or are available to measure the facilitators' "open mindedness" about this technique and support for an unbiased investigation remains at the anecdotal level. (Bomba et al, 1996, p54)

[There is a lack of congruence between] *what is communicated via facilitated communication and what is communicated via other means. Several researchers have ... noted that facilitated communication about the subject feeling uncomfortable or tense were totally inconsistent with the non-verbal behaviour exhibited by the subjects. The subjects, in fact, looked to be quite relaxed, smiled often, and appeared to be very keen to co-operate with completion of the required task.* (Hudson, 1995, p.223-224)

Regardless of the accuracy of such reports, their qualitative, observational nature undermines claims that “controlled” studies represent rigorously objective, quantitative investigations.

Issues of attitude and anxiety were also clouded by circular reasoning, as evidenced in Cabay (1994):

Of the 110 correct or incorrect responses, 26 (24%) reflected anxiety, confusion, or uncooperation. Of these, 6 occurred in the [facilitator aware] condition and 20

in the [facilitator unaware] condition, indicating a greater frequency in the [facilitator unaware] condition (p.523).

Facilitators argued that the experimental situation was stressful for the subjects, but could not explain why there were more anxiety-related responses in the condition where the facilitators were unaware of what was asked. As these data indicate that responses from facilitated communications are almost certainly the product of the facilitator, responses reflecting anxiety or refusal to be tested were likely the facilitators projected feelings of uneasiness ... (p. 524).

Clearly an alternative explanation may be that that the “unaware” condition was more stressful due to facilitators’ compromised ability to provide environmental or transactional support, as discussed under Section B.2.2 above. Another highly feasible explanation may relate to increased stress as testing sessions continued despite subjects’ spontaneous expressions of anxiety, fatigue, and requests to stop. See comments under B.2.1 above.

Similarly circular reasoning is offered by Eberlin *et al*, 1993:

Proponents of FC may remain critical of the use of experimental procedures to evaluate the validity and efficacy of FC However, they do not provide any evidence that testing necessarily destroys trust or rapport (p. 527)

This statement ignores the fact that the difference in performance between training and testing situations may indeed be evidence of this, or of other impacts of controls on the success of communication. The experimental design is inadequate to eliminate or “control” for that possibility. Once again the basis for ignoring this has, overwhelmingly, been anecdotal, not quantitative - undermining claims that these are rigorously quantitative studies

B.5 Highly contrived settings

A central criticism levelled at controlled studies is that the settings in which data were collected were highly contrived and unrepresentative of the naturalistic settings in which FC is most successful – that is, they were “*less than ecologically valid*” (Ogletree, Hamtil, Solberg, and Scoby-Schmelzle, 1993). It has been suggested that this may significantly interfere with the results by simultaneously reducing the support that can be provided by facilitators, while increasing anxiety, and thus the amount of support likely to be needed by the subjects.

Some of the contrived circumstances present in almost all controlled experiments include “blind” conditions, in which facilitators were unaware of the stimulus FC users had been asked to respond to (e.g. Beck and Pirovano, 1996, Bomba *et al*, 1996; Cabay, 1994; Crews *et al*, 1995; Eberlin *et al*, 1993), and “double -blind” conditions, in which the facilitators and FC users may have been exposed to different stimuli (e.g. Bebkö *et al*, 1996; Hirshoren & Gregory, 1995; Montee, Miltenberger & Wittrock, 1995). As noted above, such conditions would make it impossible for facilitators to provide transactional support by rephrasing a question at a simpler level as taught in facilitator training, or by encouraging or providing feedback to FC users after they had made a selection

To achieve “blind” and “double blind” conditions, facilitators may have been asked to avert their eyes (e.g. Bebkö *et al*, 1996); or wear glasses adapted to block vision (e.g.

Beck & Pirovano, 1996; Kerrin, Murdock, Sharpton, & Jones, 1998). Alternatively, the facilitator's view of the stimulus material may have been blocked by physical barriers (e.g. Bomba *et al*, 1996; Eberlin *et al*, 1993; Hirshoren & Gregory, 1995; Montee, Miltenberger & Wittrock, 1995). In some studies, facilitators left the room while the stimulus was being presented (e.g. Cabay, 1994; Crews *et al*, 1995). The latter adds a significant delay and other possible confounding factors to the test conditions. To give a picture of the level of "coming and going" involved in some studies:

... While the facilitator was out of the room, the investigator first presented the subject with a card and read aloud the question in it or told the subject the card was blank. After approximately 15 seconds, the investigator took the card back and summoned the facilitator. The investigator then left the room as the facilitator came in, sat beside the subject, and helped the subject respond. When the facilitator determined the subject had finished responding, she summoned the investigator and left. This continued until the 20 cards were presented in each condition [a total of 40 trials] or until the facilitator determined the subject was no longer cooperating (Cabay, 1994).

When auditory stimuli were presented, some facilitators were asked to wear headphones which played either speech noise (e.g. Beck & Pirovano, 1996) or white noise (e.g. Bebko *et al*, 1996; Bomba *et al*, 1996; Eberlin *et al*, 1993) to block sound, or alternatively delivered auditory stimuli that may or may not match that delivered to the FC user (e.g. Bebko *et al*, 1996; Hirshoren & Gregory, 1995; Myles, Simpson, & Smith, 1996b).

In one study, facilitator support was replaced by a mechanical device supposed to provide physical support (Edelson *et al*, 1998).

There is some – albeit limited – acknowledgment based on quantitative evidence that these invasive test conditions may have interfered with the subject's behaviour. Myles, Simpson, & Smith (1996b) interpreted their significant multiple regression finding for subjects' performance over time during the FC control phase as possible evidence that participants had been distracted by their teachers wearing headphones, or as an attitudinal reaction to being evaluated.

B.6 Inappropriate Questions

A number of studies included questions about personal preferences (e.g. "What is your favourite song?"; "What is your favourite game" (e.g. Bomba *et al*, 1996; Cabay, 1994; Eberlin *et al*, 1993). The concept of favourite may not be familiar to individuals who, due to their communication impairment and the nature of their programs, may rarely have been given the opportunity to make choices.

Others questions related to emotional reactions or required speculation about abstract concepts – for example "How do you feel about your parents"; "How do you feel about being autistic?"; "Why don't you speak?"; "What makes you happy?" (examples from Bomba *et al*, 1996 and Eberlin *et al*, 1993). Delivered under test conditions alongside other questions that clearly had right or wrong answers, these may be confronting or confusing for participants. This is not to suggest that FC users are unable to comment on such topics – merely that they are very much more likely to do so when the time and the topic for discussion have been chosen by themselves rather than imposed by a researcher.

A number of studies asked questions about activities the FC user had been involved with in another time or place (e.g. Ogletree, Hamtil, Solberg, and Scoby-Schmelzle, 1993; Cabay, 1994) – questions that may be very difficult for individuals who experience problems associated with joint attention, memory and/ or retrieval (as noted under Appendix C: Science Based Practice”).

B.7 Faulty reasoning

Examining individual studies in detail reveals many examples of faulty reasoning. I have provided only one or two examples in each category below, however many more examples can be found in the literature.

I do not pretend to have itemized all categories of faulty reasoning that may be found. Time has limited the number of studies I have been able to review for this Appendix, however I sincerely hope that the examples I discuss in this section will assist the committee to be aware of some of the reasons why “review” articles, which present only the conclusions of studies, must be treated with extreme caution.

B.7.1 Suggestions that FC should not be available to any subject who cannot pass messages under controlled conditions

Clearly, if the basic premise of the “message passing” design is rejected (see Section 3.2.1 and Appendix C: Science Based Practice), message passing under controlled conditions provides no information about an individual’s capacity for self-motivated communication in supportive, naturalistic circumstances. Despite this, comments such as the following are very commonly found in reports:

... the use of FC at this point seems only justified if done with scientifically adequate controls to ensure validation of the source of the “communication” (Eberlin et al, 1993).

Similarly:

... based on the present study’s findings which are in contrast to subjects’ reported communication abilities and the potential for facilitator influence, it appears imperative that all persons who are reported to communicate through FC be thoroughly assessed via an empirically based and controlled paradigm to evaluate the validity of such reports (Crews et al, 1995)

Clearly such statements cannot be supported if the “*empirically based and controlled paradigm*” is shown to be questionable.

Vygotsky (1978) proposed that learning occurs through socially mediated scaffolding in the “zone of proximal development” - that is, the zone between learners’ current problem solving ability and the level of ability they could achieve under adult guidance or in collaboration with more capable peers (Magliaro, Lockee, Burton, 2005, p51.). FC may be a means by which some individuals can engage in more complex and sustained social interactions and thereby access “the zone”. By definition, communication in the zone may be significantly influenced by communication partners. This is not, to my understanding, thought to render the efforts of the student valueless.

I do recognise that problems may arise when testing, rather than teaching, becomes the objective of an activity. The practice of scaffolded learning is very different from a

testing process intended to identify skills an individual can demonstrate without scaffolding.

Surely there are alternative ways of monitoring a learner's progress – for example the following description from the relationship-based program, *Floortime*, may provide a model:

It may help to think of your child's abilities as a range. Sometimes she operates at the top of her abilities, the top of the range; at other times she operates in the middle or toward the bottom of the range. The goal is not to push her to operate only at her highest level, but rather to move the entire range by degree up the developmental ladder. You want the bottom of the range to rise at the same pace as the top, so that over time both her highest and her lowest abilities are improving. Greenspan and Wieder (1998, p274)

The fact that there are challenges around testing progress should not be used as an excuse for excluding individuals with severe communication impairment from enriched learning and training opportunities. Such challenges must be addressed by educators and researchers, but they should not be made the learners' problem.

B.7.2 Suggestions that FC undermines independence

Tests conducted by Beck & Pirovano (1996) demanded a response within 30 seconds. The authors noted that one subject responded in the time limit every time with facilitation, but timely responses dropped without it. From this, they concluded – not that FC support may have assisted this participant to overcome motor planning problems that precluded a timely response – but rather that:

This difference in level of responding raises a concern that the use of FC may have been training this subject to depend on a facilitator to the degree that communication was not likely to take place without assistance. The development of his own independent communication may have been undermined through the use of FC. (p509-510)

B.7.3 Suggestions that findings supportive of FC indicate a failure of controls

Beck and Pirovano (1996) examined the use of FC to complete the Peabody Picture Vocabulary test. They found no benefit, in accord with one similar study but contrary to two others. As a result, they examined the ways in which controls applied in the two dissenting studies may have been inadequate, rather than considering the possibility that stricter controls in their own study may have interfered with the phenomena under investigation.

Their justification for this approach relied on qualitative arguments alone. Their conclusion - that: “[n]o evidence ... existed that any negative elements were present during any of the testing situations that may have interfered with the success of FC” - excludes the most obvious evidence, that the performance of FC users under test conditions was significantly more limited than may have been predicted from their performance under training conditions. (However note that this difference could not be made explicit, as the only trials actually reported by Beck and Pirovano were undertaken under “blind” conditions).

B.7.4 Suggestions that apparent success under training conditions *must* indicate facilitator influence

Bebko *et al*, (1996) reported (in the “Results” section of their paper – that is, reporting results and interpreting them simultaneously, contrary to accepted scientific practice) that data in their “*setwork*” condition: “*shows a pattern of facilitator influence for 6 students, where performance in the FC/[Facilitator] informed condition is notably higher than in the other conditions*” (p.27). The study design is unable to test the alternative interpretation, that lower results in the “*FC/[facilitator] not informed*” condition were artefacts of intrusive controls which significantly change the phenomena being investigated. If this is the case, it nullifies the author’s further interpretation, that:

... comparing performance in the FC not informed condition with the performance in the two no FC conditions, it is clear that for these students, FC did not enhance performance over what the students could do independently. (p. 27).

Bebko *et al*, (1996) also reported that performance in the FC/informed condition was higher after five to seven months of training. Their conclusion (again presented simultaneously with the results) was, not that the FC users had become more skilled communicators as a result of access to FC training, but rather that this was “*consistent with an interpretation of increased influence with increased length of time facilitating*” (p37).

Note that, while Bebko attributes “correct” responses to the facilitator, they accept that incorrect responses may emanate from subjects:

... even with the effect of [facilitator] influence, performance for most ... was still well below 100%, which indicates a less complete determination of responses by facilitators in this condition than has been reported in other studies (p30).

Bebko’s unexamined assumption, that successful communication in more natural circumstances incontrovertibly indicates facilitator influence, is not an isolated example. Eberlin *et al* (1993) also reported that communicative abilities identified by facilitators under training conditions “*disappeared under controlled test conditions*” (p. 526), and concluded that “*some facilitators influenced the subject’s typed responses while facilitating when they knew the content of questions and/or answers*” (p. 526). Once again, the experimental design is inadequate to test alternative conclusions.

It is important to note that there is nothing controversial about the finding that facilitators may influence communication. Proponents of FC fully accept that influence can occur. However, existing experimental designs cannot provide any information about how much influence occurs, or to what extent “test conditions” may increase the tendency for FC users to seek cues to the “correct” answers (see section B.7.5).

As long ago as 1994, the American Speech-Language-Hearing Association (ASHA) recognised gaps in the research around whether the results of experimental studies may be “*artefacts of testing in contrived situations*”; what were “*the qualities of “good” facilitators*”; and whether there may be “*ways of providing feedback to facilitators, through instruction, to advise them when they are inadvertently influencing communicators*” (ASHA, 1994). Experimental studies to date have made little - if any - progress on these questions.

B.7.5 Suggestions that FC users are passive intermediaries for facilitator influence

Many studies provide undeniable evidence of facilitator influence. This comes from double-blind trials in which the FC user types a response appropriate, not to the stimuli with which they have been presented, but to that seen and heard by their facilitator (e.g. Bebko *et al*, 1996; Cabay, 1994). Conclusions drawn from such findings generally cast FC users as passive intermediaries in the communication process. This interpretation ignores the possibility that at times – for example, when unsure what is expected of them - FC users may actively seek cues from their facilitators.

This suggestion may be partially supported by Bebko *et al* (1996), who reported:

... an "abdication" pattern of responding ... for some students, in which high performance observed with independent responding was lessened on trials when FC was introduced (P20).

They conclude that their findings:

*... may not entirely be a result of the facilitators' (unconscious) influence - the child may make him/herself more susceptible to influence by increased passivity and at least partial abdication of control over his/her communication. (Bebko *et al*, 1996, p39)*

(It should be noted that the suitability of FC as a communication strategy for subjects in Bebko *et al* (1996) does not appear to have been appropriately assessed, as those referred to possessed independent, alternative means of communication more appropriate to the task. Their passivity may simply have reflected their confusion when expected to key with facilitation.)

Research also shows that facilitator influence may be significantly reduced through best practice and appropriate facilitator training (for example, Cardinal, Hanson, Wakeham, 1996).

It may be more likely to occur under intimidating assessment conditions involving tasks designed - not to reduce communication frustration – but merely to “test” an individual’s ability to pass messages or answer questions that hold little or no emotional value to them. If so, it is unsurprising that there is evidence that shows facilitator influence in many controlled “message passing” or confrontational testing experiments.

It seems reasonable to assume that passivity and cue seeking is less likely to occur when an individual’s communication is motivated by their own needs or desires. Textual analysis shows that FC users are more inclined to write about feelings and emotions, compared with neurotypical peers who describe activities (Bernardi and Tuzzi, 2011a). Such communication is very different from the message passing or confrontational testing activities that usually form the basis for controlled experiments, and from the “mands” that are the primary goal of the early (and often, the only attained) levels of PECS and other AAC strategies.

An experiment designed to explore the nature of “motor automatisms” (Wegner, Fuller and Sparrow, 2003) may support the suggestion that closed questions with simple answers are more open to facilitator influence than more complex open-ended communication – please see Section B.2.9. It should be noted, however, that in the early stages of FC training open ended communication is very difficult for many individuals.

Scaffolded communication, including “set work”, is likely to be required to assist FC users develop skills. (Different “levels” of communication are detailed in facilitator training, and some information on this topic is presented in Section B.2.2.)

As Biklen and Duchan (1994) observed:

The aim is to understand the facilitated exchanges as a highly complex activity in which different messages are negotiated in different ways, with varying degrees of contribution from each of the partners. The experiential perspective takes as given that individuals influence one another. Indeed, communication is, by its very nature, an effort by the partners to influence one another – to request responses, to elicit answers, to persuade to a point of view, to teach new content, to support one another’s efforts. It is unwanted, manipulative or oppressive influence that needs to be guarded against, not influence itself. (p178)

In those situations where the communicator types what the facilitator sees, does the communicator know he or she is doing it? If it is conscious, how does the person speak of it – as cue seeking, as influence, as manipulation, or as something else? (1994, p179).

Similarly, Grayson (1997, p232) said:

Facilitator influence must go on, since quite apart from the physical contact, influencing one’s communication partners is a feature of any interaction. It is important to recognise this, for it reminds us to take one step back from the ‘all-or-nothing’ feel to some of the FC literature. The really difficult questions that need answering are not as simple as ‘does facilitator influence go on’? Of course it does. What we need to know is how does influence happen, how much of it is there, when and where does it occur, and does the intervention (on balance) infringe or enhance the rights of the client?

Research shows that influence may be significantly reduced through best practice and appropriate facilitator training (e.g. Cardinal, Hanson, Wakeham, 1996) Awareness that facilitator influence can happen has significantly informed the development of “best practice” in Queensland. It is reflected in:

- rigorous facilitator training;
- emphasis placed on independent communication as the ultimate goal of Facilitated Communication Training (FCT);
- development of protocols to (for example) collect ongoing validation data; and
- development of a rigorous protocol for validating controversial or life-changing communications.

Despite the strong emphasis on “best practice” in facilitator training, decisions about data collection and practice remain a matter for the individual FC user’s family, lead agency, or facility – whoever takes primary care for his or her educational, living or recreational arrangements where FCT is practiced.

I would hope that poor practice within an agency would be addressed by management implementing improvements and safeguards – not by a fatalistic belief that practice cannot be improved and that individuals with severe language impairment should therefore lose access to their communication system.

B.7.6 Suggestions that literacy is unexpected in this population

Crews *et al* (1995) found the lack of success for their subjects unsurprising, saying:

“It seems counterintuitive that these institutionalized individuals could be able to spell/type words and produce complex phrases/sentences via FC when such literacy skills prove impossible for many illiterate individuals with significantly higher levels of measured intelligence and formal education.” P.212

Similarly, Cabay (1994) refers to:

... the bold implication that, with little or no formal education, autistic children have acquired highly developed general knowledge, reading and writing skills that are only waiting to be uncovered through facilitation (p. 518).

More recently, similar views have been echoed, both by the Queensland reviewers and by the SPA Clinical Guideline:

The Research Team was ... told by FC supporters ... that for autistic people literacy is created by the environment (e.g. watching TV or siblings), not through training or other traditional/educational process. Again, these views were debunked by the experts on the basis of the research evidence (Mazerole and Legosz, 2012, p65).

FC has generated controversy as FC users' communications have contradicted preconceived beliefs of their abilities and the authorship of messages has been questioned (SPA, 2012, p.30).

Recent research challenges the longstanding presumption of a strong and common relationship between autism and intellectual disability:

... a thorough analysis of the published evidence ... found that only 26% of all claims [regarding the rates of intellectual disability in individuals with ASD] traced back to empirical data. However, in many of these studies, researchers had arbitrarily assigned IQ scores in the severe to profound range of ID to children who were untestable, and then proceeded to use both assigned and “real” scores to calculate prevalence rates. In the end, only 15.7% of all claims traced to studies whose authors based their prevalence estimates on real data only and utilized specific psychometrically valid methods to assess intelligence (Edelson, 2006, cited in Mirenda, 2008, p223)

Further:

... almost all published prevalence studies of PDD since 1998 ... have found that no more than half of individuals with PDD have an intellectual disability, with most indicating rates in the range of 26–40% (Mirenda, 2008, p224).

From time to time hyperlexia – a condition associated with precocious decoding skills – is mentioned as a possible mechanism behind the unexpected literacy seen in some FC users (e.g. Donnellan, Sabin and Majure, 1992, cited in Mostert, 2001). I am unaware of any research that seeks to examine this issue directly, however it does appear to be worthy of further investigation.

Hyperlexia is a well recognised condition characterized by early reading skill developed in the absence of explicit instruction, and advanced word recognition ability compared with more limited comprehension skills. It generally occurs in the presence of a

developmental disorder of communication, most commonly an autism spectrum disorder. (Turkeltaub, Flowers, Verbalis, Miranda, Gareau, and Eden, 2004).

Although hyperlexic children may not comprehend all that they read, print can still become an important route by which they communicate because attention to text is more reliable than attention to voice In fact, outcomes for verbal ability and IQ are better for autistic children with hyperlexia than for other autistic children ... , possibly because reading provides an additional route for communication and socialization Gaining insights into the neurobiological basis of reading in hyperlexic children will be a crucial step to understanding this disorder and may lead to the development of remediation strategies for autism. (Turkeltaub, Flowers, Verbalis, Miranda, Gareau, and Eden, 2004, p12).

Reliable prevalence estimates for hyperlexia are not available, however the high (not universal) incidence of literacy in the absence of explicit instruction among FC users may suggest a higher prevalence in that population. As such, research into the underlying mechanisms of hyperlexia may enhance our understanding of the FC population.

In particular, links between the comprehension difficulties identified in hyperlexia and cognitive differences identified in the FC population may be of interest for future research. Further, interventions targeting hyperlexia, such as the Lindamood-Bell programs “Talkies” and “Visualising and Verbalising”, may potentially be beneficial if the programs can be adapted for FC users.

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

As early as 1994, in their chapter of a volume largely devoted to debunking FC, Prizant *et al* (1994) noted that hyperlexia may provide a key to understanding the phenomenon, 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).*

B.7.7 Conclusions based on inadequate data

In some studies, conclusions clearly went far beyond the data that had been generated. For example, when Edelson *et al* (1998) found that their subjects were unable to point with a mechanical device more accurately than they could independently, this was interpreted as meaning “no evidence for the efficacy of FC” (p.157) rather than no evidence for efficacy of the device. (Note that one of these subjects had previously successfully completed a “blind” message passing trial of FC!)

The design of Edelson *et al* (1998) differs from most other experimental studies, so this may be the only example of this particular form of faulty reasoning. However, the vast bulk of other studies were very similar, so the following examples are highly likely to have been replicated many times over.

Beck and Pirovano (1996) provide an example of conclusions that go well beyond the data generated by their study. They selected twelve subjects who had been reported to have used FC with some success for at least a year. When the Peabody Picture Vocabulary Test was administered to them using FC under controlled conditions, however:

No subject achieved a score high enough to be converted to a standard score or a percentile. Some subjects also did not score high enough to be able to convert their scores to age equivalencies (p.504).

This did not lead the authors to question whether the test may not be appropriate for these subjects – instead they persisted and used raw scores to compare subject's response levels on various conditions.

Twelve subjects were tested with, at different times, visual and auditory stimuli. The authors described this as “*24 opportunities to show increased ability with FC*”, and noted that “*improvement was noted 16 times*” (p.509). Most of these apparently positive findings, however, can legitimately be disregarded as only three met the conditions required to be statistically significant.

The statistical weakness of this study illustrates the difficulties that must be overcome if controlled, quantitative studies are to provide legitimate data in the behavioural sciences. An increase in the number of trials may have increased statistical reliability of the results; however such an increase is likely to be problematic given the nature of the task. Excessive repetition of simplistic tasks is likely to produce confounding behaviours from subject for whom the task is essentially meaningless or uninteresting, or who take the repetition to indicate that there was something wrong with their earlier responses, and react accordingly. Alternatively, subjects may learn from the repetition so that conditions change as testing proceeds.

Instead of acknowledging that no conclusion could legitimately be drawn from results that are not statistically significant, the authors state only that the apparently positive results cannot be taken as support for the validity of FC. This masks the obvious fact that the results can not be taken as evidence against FC either.

Similarly, Bomba *et al* (1996) report that, for 13 of their 14 participants, no item was answered correctly in either their pre-training or post-training tests. The 14th participant was able to answer questions in the posttest, but his performance was well within the range of his independent abilities. The authors of this study acknowledge that the subjects selected for their study may not have been “*appropriate for successful FC*” (p.54), yet still concluded that their results:

... fail to confirm the qualitative reports of success with FC and provide support for the quantitative studies that indicate that many individuals with autism are unable to communicate independently through FC (p53).

Note that proponents suggest only that FC may allow *some* individuals with autism to communicate through FC. Were this to be taken as a working hypothesis, demonstrating

that there are individuals with autism who may not benefit from FC does absolutely nothing to falsify the hypothesis. This is particularly so when the problems associated with selection of participants for these studies is taken into account (see B.3, Selection of Subjects). Yet Bomba *et al* (1996) is included in review articles such as Mostert (2001), listed with “*studies refuting FC*” (p. 292).

B.7.8 Slipping from data to interpretation

In section B.7.4 I noted the habit of some authors, in papers that purport to follow the format of scientific reports, to report data and simultaneously offer their interpretation under the heading of “Results”. The observation that this is contrary to accepted scientific practice is not merely pedantry. The convention that data should be presented separately, and that interpretations may be offered under the heading of “Discussion”, allows more explicit consideration of whether there may be competing explanations for findings revealed in the data.

To quote Emerson, Grayson and Griffiths (2001):

It may be that in some domains the most likely interpretations of “did not” is “could not”, with the “could not” referring directly to the hidden entity under investigation. But in the domain of communication disabilities, where it has always been clear that people have difficulties with doing communication, we would argue for caution in moving too readily from observations of performance to judgments about competence.

B.7.9 Positive results ignored

Bebko *et al* (1996) appeared to report evidence of benefit from FC under their “headphones” condition. When students and facilitators heard different stimuli through headphones, results for all but one student showed:

... either the students were determining the response being made (8 of the students ...) or ... responses were essentially randomly distributed among the alternatives available, either case indicating no facilitator influence” (p. 34).

Yet when Bebko *et al* (1996) was listed by Mostert (2001) as a study showing some support for FC, the authors published a shrill denial (Bebko, Perry, & Bryson, 2003). The grounds of this denial may be valid – there were no “unfacilitated” headphone trials in the original study, and when this was rectified at follow-up after five to seven months of additional FC use, it seemed that FC provided no advantage over independent responding. There was, however, no discussion of the possibility that these results may reflect the benefits of five to seven months of additional FC training: that is, improved ability to respond independently to simple tasks due to improved motor planning.

Similarly, three subjects in Beck and Pirovano (1996) demonstrated statistically significant benefits of FC. These results have been summarily dismissed by arguments that the benefit conferred by FC – as measured by the Peabody Picture Vocabulary Test under controlled conditions – was not adequate to warrant use of FC – in one case because the subject could achieve the same result independently “*given appropriate stimuli*”, and in the other two cases because, although FC had shown seven and 9 months improvement in age equivalent performance, it did not bring them close to their chronological age. No effort was made to discuss the validity of applying the test to these subjects, nor to compare the student’s performance under test conditions with their

performance under supportive, naturalistic conditions – arguably the more important factor in determining whether FC may be of benefit to their future development.

Crews *et al* (1995) reported “*limited positive outcomes were observed in two individuals ... however, the results were questionable in one subject*” (p.213) Even these limited findings should be adequate to falsify an hypothesis that “FC does not work” – however Crews *et al* (1995) is also firmly listed by Mostert (2001) among “studies refuting FC” (p.293).

B.8 Conclusion

To conclude, although this Appendix has reviewed only a very small proportion of the experimental studies undertaken over the past two decades, I hope it has illustrated the poor practice and faulty reasoning that renders the controlled message passing/ confrontational testing design fatally flawed.

I also hope this will serve as a guide to the Committee in their reading, as many of the flaws I have outlined are repeated again and again throughout the literature that is habitually cited when FC is proclaimed as pseudo-science.

It must be understood that this research has been based on experimental practices that bear little or no resemblance to FC “best practice”. The data thus obtained is clearly invalid.

Conversely, the qualitative, observational research must, at the very least, show that there is something here to be researched and understood. As Isaac Asimov (the well-known US science fiction novelist & scholar) is said to have quipped:

The most exciting phrase to hear in science, the one that heralds new discoveries, is not “Eureka” but “That’s funny” ... (Kline, 2008, p236).

Appendix C Science Based practice

In his 2010 keynote address to the SPA national conference, Lof modified the usual definition of EBP to embrace “*Science Based Practice ... [that is,] the use of scientific thinking and procedures/methods, and interpretation of theories and models when making clinical decisions*” (Lof, 2011, p194).

In accordance with this view, in the absence of quality research specifically targeting FC users, research on overlapping populations, including research on sensory and movement differences, informs practitioners who work with clients who use FC.

C.1 Failure of the evidence-base

One of the frequently stated drawbacks of [evidence-based practice in the field of Speech-Language Pathology] is that many of the treatments used clinically do not have peer-reviewed, empirically-based studies supporting their efficacy/efficiency This being the case, what we do have are well-established theories and principles that have been rigorously studied scientifically. ... If there is a scarcity of data on a specific topic, there probably are well established and tested theories that can help direct clinical practice. (Lof, 2011, p194)

As discussed under Section 3 “Research Evidence”, Facilitated Communication *does* have empirical support from peer reviewed experimental and naturalistic studies, although this is commonly disregarded in the face of a large body of negative experimental findings dating from the 1990s. Why such discrepant results?

Experiments conducted during the 1990s had many design flaws (see Appendix B). The most significant flaw, however, was the basic premise on which the vast majority of experiments were predicated: that the ability to pass messages under highly contrived circumstances is a reasonable test of the efficacy of FC (see Section 3.2.1).

It is generally known by those who live and work with FC users that many find message passing difficult. Some speculate that this may be due to a lack of opportunity to practice and shape the behaviour through the innumerable reciprocal interactions available to verbal children. Others wonder if the answer may be more complex, and this is the possibility explored in this section of the submission. Regardless of the reason, testing FC users’ ability to communicate using a task that is so clearly problematic for many *must* be questioned.

Alternative means of evaluating the phenomenon have been identified and used in other studies. Examples include use of specialist eye-tracking equipment and fine-grained video analysis to demonstrate that an FC user was making visually guided, intentional movements towards the letters he selected (Grayson et al, 2011); and statistical analysis of texts to identify distinctive lexical features (e.g. Bernardi & Tuzzi, 2011a). Please see Section 3.2.5).

It is recognised that these alternative experimental designs may not be suitable for application across the whole population of FC users – due, for example, to visual differences that may affect some individuals (e.g. see Yoshida, Nakamizo, & Kondo, 2011) or to different levels of literacy within the FC user population – however the

pressure to overcome such difficulties must be on those who design experiments, not on the subjects.

By rejecting message passing and confrontational testing as a legitimate basis for experimental designs, I am not suggesting that FC users should not be assisted to develop the skills needed for these tasks – only that the focus must be on teaching, not testing. I *would* argue that interventions must address underlying mechanisms, rather than teaching the skill in relative isolation. However, research is needed to clarify what the underlying mechanisms may be, and such research is unlikely to proceed while the communications of FC users are not accepted as genuine reflections of their cognitive processes.

C.2 Barriers to Future Research

The ability to pass messages relies on considerably more than an ability to communicate. It also demands cognitive and processing skills which, according to research undertaken since the 1990s, may not develop along typical pathways in individuals who have severe sensory and movement disorders. This is not to suggest that affected individuals are cognitively impaired, merely that they may have cognitive differences that may create difficulty in tasks that are not directed by their own interests, including message passing and confrontational testing.

Research supporting this argument has not focused directly on FC users, but on the overlapping population of individuals with autism. For this reason it must be approached cautiously: seen as providing “*well established and tested theories that can help direct clinical practice*” rather than direct evidence that message passing and confrontational testing are not appropriate tests of FC.

The lack of research directly focused on FC users may reflect the acknowledged difficulty of studying cognitive function in individuals who have complex communication needs. Such barriers seem insurmountable if “think aloud” protocols cannot be used to monitor cognitive function because researchers do not accept subjects’ communication as genuine.

The major barrier to research, however, is likely to be the barrage of vitriol hurled, via both professional and popular media, at any researcher who dares to show an interest in FC. This bigotry must be put aside before any progress can be made.

C.3 FC users who are not autistic

Individuals with autism are only one group within the “FC user” population, just as FC users are but a small sub-group of the autistic population. Why might broader autism research help us understand cognitive differences seen in FC users, regardless of their diagnosis?

The answer hinges on movement disturbance. As observed on the website of Queensland FCT Inc,

“People who may be candidates for Facilitated Communication Training are likely to be people who have movement disturbances which prevent them from pointing for communication purposes”. (Remington-Gurney, 2012)

Movement disturbance, therefore, is a unifying characteristic of FC users.

The suggestion that autistic individuals may experience movement disturbance was highly controversial in the 1990s (see, for example, Jacobsen, Mulick and Schwartz, 1995). Since the turn of the century, however, it has increasingly been the subject of research and is now very widely accepted. For example, Mostofsky and Ewen (2011) note that Kanner's original description of autism included reference to motor deficits. They go on to cite clinical and research evidence that children with autism have particular difficulty learning skilled motor tasks, and have a high incidence of abnormalities in basic motor skills such as gait, posture, balance, speed, and coordination.

On the other hand, innate reflexive capacities (e.g., sitting up and walking) are less likely to be affected than skilled motor tasks such as praxis and motor imitation (Mostofsky and Ewen, 2011). As a result, the appearance of autistic FC users may superficially belie the presence of severe movement disorder. Within the autistic population, however, individuals who have not developed the skills to independently point for communication purposes are likely to be among the most severely affected by movement disturbance, and are therefore likely to be the most severely affected by any flow-on developmental effects.

Please see Appendix A, which cites further research evidence of movement disorder in autism.

The research discussed below shows that the impact of motor and sensory-motor difference on development may go a long way towards explaining aspects of cognitive processing identified as characteristic of autism. If the cognitive development of autistic individuals has been impacted by underlying sensory and motor differences, it seems reasonable to speculate that sensory and motor differences in other populations may have similar impact. This may explain similarities in cognitive processing – including difficulties with message passing and confrontational testing – seen in FC users regardless of their diagnosis.

This suggestion remains speculative until examined directly by appropriately designed research. As noted by Rogers and Bennetto (2000):

Other groups of children come into the world with motor systems that may be much more impaired than those of children with autism. The motor skills of people with autism, including imitation, need to be examined in relation to matched groups with developmental dyspraxia, cerebral palsy, and other kinds of motor impairments to reveal whether there is any unique aspect of the deficit in autism (Rogers and Bennetto, 2000, p.99).

C.4 Twenty-first century developments

A book published nearly twenty years ago (Shane, 1994) was, remarkably, the only source cited by Lof in support of his statement to Australian Speech-Language Pathologists that “*facilitated communication does not work*” (Lof, 2011, p192). The editor of that book, speech pathologist Howard Shane of Children's Hospital Boston, continues to be an ardent critic of facilitated communication and has recently appeared as an expert witness in a US court case involving FC. When a prosecutor questioned his expertise on the basis that it had been 15 years since he had researched FC, his reported response was “*It'd be like suggesting that we continue to study cold fusion or bloodletting. When it's over, it's over*” (Gomstyn, 2012)

Thankfully not all researchers are so obdurate.

One chapter in Shane (1994) was authored by Prizant, Wetherby and Rydell. Their greatest criticism of FC literature at that time was that it contained “*no in-depth consideration of the body of accumulated research on cognitive differences*”. (Contemporary proponents of FC tended to explain difficulties with message passing and confrontational testing in terms of an indistinctly defined “word finding problem” rather than by reference to extant, deficit-centred models of cognition in autism.)¹

Prizant *et al* (1994) also asserted that “*a primary motor disability*” could not explain the “*patterns of cognitive processing*” that were different in autism (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). Chapter authors in this 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. More recent research has supported these findings.

In this section of my submission, I argue that this and related research supports the practice of Facilitated Communication, and suggests a theoretical basis for the argument against message passing or confrontational testing as legitimate means of testing communicative ability in the FC population.

C.5 Developmental Detour

The Dynamic Systems model of child development characterizes developmental change as “*multicausal, fluid, contextual, and self-organizing*” (Smith and Thelen, 2003, p343). Further:

[T]he dynamic view considers bodily movement as a central mechanism in development, co-equal with the processes of perception and cognition and indeed inseparable from them. This means that the foundations of complex human thought and behaviour have their origins in action and are always embedded in a history of acting. ... [M]any of the problems associated with developmental delays or disorders may have common origins in deficits of basic perceptual-motor processes that distort children's' interactions with the world around them, and ... these deficits can cascade into serious problems in functioning. (Thelen, 2004, p49)

¹ Recent imaging studies (e.g. Kana, Keller, Cherkassky, Minshew, & Just, 2006) have demonstrated that disrupted brain connectivity in autism is likely to disrupt the connections between verbal and imaging codes. Reference to Paivio's Dual Coding Theory (DCT) (Clark & Paivio, 1991) provides an explanation of how such disrupted connectivity may impact word finding when linking images to words and words to pictures. It also outlines the highly personal way associative connections are laid down within and between the verbal and nonverbal systems, dependent on individual experience and context. This may be a fruitful avenue for research into why FC users are more easily able to follow their own chain of thought related to topics of personal relevance, and have difficulty with confrontational tests set by researchers.

“By the time a child is diagnosed ... the original source of the delays may be entirely masked by the emergent and compensating behaviour” (Thelen, 2004, p71).

This dynamic approach to understanding development underpins other theories, for example Greenspan’s Affect Diathesis Hypothesis:

“What later looks like a primary biological deficit may ... be part of a dynamic process through which the child’s lack of affective reciprocal interactions has intensified specific, early, biologically-based processing problems and derailed the learning of critical social and intellectual skills.” (Greenspan, 2001, p.5)

As discussed in Sections C.10 and C.11 below, *“lack of affective reciprocal interactions”* – a deficit central to Greenspan’s understanding of autism - may be influenced by or even caused by sensory-motor problems.

A dynamic systems model of alternative developmental pathways, therefore, calls for an understanding of early, biologically-based sensory and movement problems, and the developmental detour they may engender. Such understanding may help explain cognitive differences in the FC population – including those that render message passing and confrontational testing inappropriate as tests of communicative competence. Most importantly, such understanding may point the way to better targeted, more effective interventions.

C.6 Sensory Differences

In 1992 – just as controversy over Facilitated Communication was about to erupt in the United States and Australia – a book by Gillberg and Coleman noted similarities between autism and deprivation syndrome. The authors thought the link may be a similar lack of sensory input in each condition. In deprivation syndrome, the lack of input is due to an impoverished sensory environment, but it was suggested that the same effect may occur when a baby cannot benefit from his normal environment because of some impairment in his ability to process incoming sensory stimuli (Gilberg and Coleman, 1992).

By the end of the 1990s sensory disturbance in autism had been well documented, as had its potential to impact arousal, affect, action, attention – and, in consequence of these - social interaction (e.g. Dawson & Watling, 2000; Baker, Lane, Angley & Young, 2008). The underlying mechanisms may vary, and the developmental implications may be difficult to map or quantify. Even at the most basic level, however, the widespread incidence of sensory disturbance in autism should lead us to question whether the sensory information most significant to neurotypical individuals – including researchers seeking to administer “message passing” or confrontational tests – will be equally prioritized by individuals with atypical sensory perception and processing.

If not, “message passing” and confrontational tests must be seen, at the very least, as problematic for a population with a high incidence of sensory disturbance.

C.7 Internal Action Models

In the mid-twentieth century, renowned developmental psychologist Jean Piaget described what he called a sensory-motor stage of cognitive development, in which individuals learn specific skills and develop cognitive faculties by performing actions and interpreting the sensory feedback that results (Mostofsky & Ewen, 2011). A more recent,

brain-based description of this process uses the term “internal models” (e.g. Shadmehr and Mussa-Ivaldi, 1994; Shadmehr and Krakauer, 2008).

We suggest that a function of the cerebellum is system identification: to build internal models that predict sensory outcome of motor commands and correct motor commands through internal feedback. A function of the parietal cortex is state estimation: to integrate the predicted proprioceptive and visual outcomes with sensory feedback to form a belief about how the commands affected the states of the body and the environment. A function of basal ganglia is related to optimal control: learning costs and rewards associated with sensory states and estimating the “cost-to-go” during execution of a motor task. Finally, functions of the primary and the premotor cortices are related to implementing the optimal control policy by transforming beliefs about proprioceptive and visual states, respectively, into motor commands. (Shadmehr and Krakauer, 2008, p359.)

Mostofsky and Ewen (2011) build on this research, arguing that what they call “internal action models” are sensory-motor programs central to the development of a wide range of human behavior. In their model, anomalous action model formation may derail development of motor, communicative, and social behaviour in autism. In fact, they go so far as to title their paper: “*Altered connectivity and action model formation in autism is autism*”. Their experiments show that, during motor learning, individuals with autism place a greater than normal reliance on proprioception while discounting visual feedback. They explain this by reference to research showing local overconnectivity and global underconnectivity in the brains of individuals with autism. (Proprioception is mediated by short-range connections, while vision is mediated by long-range connections.) Problems with sensory integration ensue.

An alternative brain-based explanation for sensory disturbance in autism centres on the suggestion that some autistic individuals may be chronically fed “bad data” from disruption of a multisensory feedback loop mediated by the cerebellum (e.g. Kern, 2003). According to Akshoomoff (2000, p185): “*[t]he cerebellum is the most consistent neuroanatomical site of abnormality identified in neuroimaging and autopsy studies of individuals with autism*”. Koziol, Budding & Chidekel (2011) suggest that cerebella dysfunction may disrupt continuous sensorimotor interaction with the environment on which a semantic understanding of “allocentric” space is based. (Their model is discussed further in Sections C.13 and C.14, below.)

As Akshoomoff (2000, p185) noted:

It is important to consider that the brain of a child with autism has developed differently throughout prenatal and postnatal development. Therefore, phenotypic differences are to be expected and make it challenging to trace the origin of these differences back to infancy.

Given this observation, and the diversity that is to be found on the autism spectrum, is unlikely that any single mechanism will be found to account for disruption of sensory-motor programs, or that the resultant “developmental detour” will be entirely predictable. Different underlying mechanisms may none-the-less lead to similar outcomes.

Both over reliance on proprioception rather than visual feedback during motor learning (as described by Mostofsky and Ewen, 2011) and problematic sensory-motor interactions with the environment (as described by Koziol et. al. 2011) will clearly have significant

implications for the “downstream” development of other skills – including social skills, reliant as they are on visual information and feedback from the environment. Mostofsky and Ewen conclude that affected individuals may develop a “dyspraxia” for social and communicative skills, in addition to praxis and imitation impairment.

C.8 Praxis

Praxis refers to the planning, execution, and sequencing of movements (Ayes, 1985, cited in Rogers and Bennetto, 2000). Anzalone and Williamson (2000, p150) suggest that praxis encompasses three steps: ideation, motor planning, and execution, each of which is heavily dependent on sensory information.

Ideation

Ideation involves the formulation of a goal. Anzalone and Williamson (2000) note that formulation of a goal is reliant on sensory modulation and flexible interaction with the environment – factors likely to be impacted by unreliable or atypical sensory perception, processing, and integration. Sensory difficulties are common in autism, as discussed in Section C.7.

Motor Planning

Motor planning refers to the planning, initiation and sequencing of motor tasks needed to accomplish an identified goal. It is dependent on sensorimotor awareness of the body – a “body scheme” – normally acquired through past movement experiences. Body scheme provides the sensory basis necessary for the anticipatory, or feedforward, control of movement (Anzalone and Williamson, 2000.)

Clearly, the body scheme is likely to develop differently in individuals whose past movement experiences have been compromised by sensory and/or movement differences. As motor planning is dependent on body scheme, it follows that individuals with sensory and/or movement differences are likely to develop difficulty with motor planning.

Anzole and Williamson (2000) suggest that body scheme may be enhanced by increasing somatosensory input (i.e., pressure touch and proprioception) through resistive gross motor activities.

Arguably, the touch provided by a facilitator in FCT may similarly serve to enhance body scheme. In FC, physical support consists of backward pressure for the communicator to push against (activating proprioceptors); light pressure on joints to increase proprioceptive awareness; or simply touch to provide the individual with a point of reference in their body scheme.

Mostofsky and Ewen (2011) and Thelen (2004) may provide starting points for increasing our current, limited understanding of the role of touch in FC.

Mostofsky and Ewen (2011) have suggest that proprioceptive feedback may be a particularly effective means of improving skilled behavior in the autistic population due to their greater than normal reliance on proprioception rather than visual feedback during motor learning.

Thelen (2004) reported that perseverative reaching in normally developing infants can be disrupted by disrupting the way the arm feels to the infant. She added small weights to infant's arms to make them heavier - resulting in inhibition of the typical perseverative response and a shift to a new, more appropriate response. Perhaps the physical support provided through FC helps limit perseveration via a similar mechanism.

Execution

The final step in praxis is execution: carrying out the planned action. This step is influenced by the individual's motor development, skill and coordination. Anzole and Williamson (2000) state that execution may be improved by targeted practice of motor skills.

Targeted practice may be highly problematic for individuals who have movement differences, or whose sensory differences so compromise their awareness of their environment that they have little motivation to practice motor skills. Support provided through Facilitated Communication may, for some individuals, help overcome such difficulties - allowing practice and resulting in improvements over time.

Thus, the implications of sensory difference may go well beyond the basic question of whether affected individuals perceive and attach value to environmental stimuli in a manner comparable with neurotypical individuals. Sensory difference may also lead to problems with goal setting, body scheme, motor planning and execution of motor tasks, resulting in dyspraxia. Further, such difficulties are likely to have cascading impacts on an individual's development and cognitive profile, as discussed in the following sections.

C.9 Imitation

Motor imitation, like praxis, involves formation and storage of spatial/ temporal representations of action, and also selection and sequencing of the resulting motor program. To achieve motor imitation:

- Movement must be visually perceived and encoded into working memory;
- The visual stimulus must be translated to a proprioceptive stimulus and mapped onto one's body;
- A movement plan must be formed, executed, and monitored against remembered visual stimulus. Errors must be perceived and corrected;
- Imitation also demands an effort to match "vitality affects" – the rhythm, speed, flow and other aspects of the movement that convey its emotional tone. This involves perceiving the affective message in the movement and encoding the visual stimuli onto an affective map. (Rogers and Bennetto, 2000, p99)

By the early 1990s a number of studies of young children had already suggested that an impairment in the ability to imitate another person's movements may be a core deficit in autism. (Rogers and Bennetto, 2000). By the turn of the century these findings had been extended:

Studies involving imitation skills of higher-functioning older children, adolescents, and adults with autism report continuing problems with accuracy and quality of imitation. This indicates what may be a lifelong impairment, present in the youngest children with autism examined (20 months), virtually universal in the groups studies, and persistent across development. The imitation

deficit thus continues to meet most of the criteria of a primary neuropsychological deficit. (Rogers and Bennetto, 2000, p100.)

C.10 Relatedness

The implications of difficulties with praxis and imitation may be considerable. Rogers and Bennetto (2000) describe 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 note 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)

This sentiment is reflected by Wetherby, Prizant and Schuler (2000, p128), who emphasize:

... the importance of participation in shared cultural events and the situational relevance of utterances. ... 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.

It seems likely that the proximity and physical contact between facilitator and communicator in FC support improves synchrony, joint attention, and the experiences of emotional contagion. Further, access to a strategy that allows communication “on-the-go” in real contexts has powerful potential to promote functionality, relevance, and inclusion.

It is clear that confrontational testing, including message passing tests in highly contrived settings, may challenge the emotional support that is emphasized in FC.

C.11 Social-cognitive behaviour

Carpenter and Tomasello (2000) describe a social-cognitive revolution around the first birthday of typically developing children, evidenced by such skills as referential looking (i.e. gaze alternation between object and adult); declarative pointing and showing; looking where others look and point; and social referencing. More advanced skills follow: imitative learning of the use of tools and artefacts (including linguistic symbols), and perception of intentional action. (Carpenter and Tomasello, 2000)

Absence of such skills has long been identified among early markers for autism (for example, Gillberg & Coleman, 1992, Hedley, Young, Gallegos and Salazar, 2010). It should be noted that there is a significant motor component to such skills.

As these skills develop in the neurotypical infant, so does understanding of others as intentional agents whose attention, emotion, and behaviour to outside objects may be actively followed into and shared. The child learns to see the adult's overt actions as composed of both a goal and of a means for attaining that goal. Research shows that neurotypical children then actively choose the adult's means of goal attainment in preference to other approaches (Carpenter and Tomasello, 2000).

Clearly difficulties with relatedness, as described in the previous section, will interfere with development of such social-cognitive behaviour.

Mostofsky and Ewen (2011) agree that social skills are acquired through observation and imitation of other people's actions, but also note that internal action models allow neurotypical individuals, via "feedforward" mechanisms, to infer others' intentions. Children with autism demonstrate, not only impaired ability to perform skilled gestures (expressive praxis skills), but also impaired interpretation of gestures in others ("receptive" understanding of other people's performance of the skills). Mostofsky and Ewen suggest that a single underlying mechanism – anomalous patterns of internal action model formation in autism – may account for both.

They conclude that theory of mind, the mirror neuron system, motor dyspraxia, and abnormal sensory responses can all be understood through anomalous patterns of internal action model formation in autism – an understanding of sensory-motor learning and its potential impact on social understanding that once again highlights the difficulty an affected individual may face when presented with a "message passing" task or confrontational test.

C.12 Attention

Some individuals with autism are known to have over selective, narrow attention, whereas others have diffuse, nonselective attention. Some have deficits in rapidly orienting and shifting their attention – skills crucial for cognitive and social information processing. (Anzalone and Williamson, 2000) These differences in attention and processing may be influenced by – to a greater or lesser degree in different individuals – sensory and motor differences. Note, for example, the significant motor component of the orienting response. Interactions with affected individuals must take attention differences into account.

The theory of "weak central coherence" illustrates one way in which sensory differences may impact on attention and processing. Perceptual abnormalities such as sensory hypersensitivity are thought to result in "context-free" processing, in which individuals rely more heavily on "local" or piecemeal processing such as item-to-item chaining, at the cost of normal global processing modulated by expectation and context. (Happé and Frith 2006)

Clearly "context-free" processing would be extremely problematic in a message-passing test.

Most models examining the impact of sensory difference on attention, including “weak central coherence”, emphasize exteroceptive (or “outside-in”) sensory information. More recently, Mundy, Gwaltney & Henderson, (2010) have expanded this to include self-referenced sensory information: interoception (awareness of ones own physiological states) and proprioception (awareness of the position, location, orientation and movement of the body).

Mundy, Gwaltney & Henderson (2010) suggest that typically developing infants gradually develop the ability to socially coordinate mental attention for the purpose of sharing experience. This occurs through frequent, socially embedded practice which is both a cause and a consequence of ongoing neural maturity (and which is likely to be more difficult for an individual who has difficulty with relatedness, as described in section C.10.) The co-activation of self- and other-processing systems becomes more efficient through practice - (neurons that fire together wire together), thus providing the basis of social executive function and volitional, planned and goal-directed behaviour. Mundy, Gwaltney & Henderson propose that joint attention tasks (of which message passing and confrontational testing are clearly examples) require individuals to attend to and process:

- information about an object or event
- information about the environment including their social partners’ attention and behaviour related to the object/ event; and
- self-referenced information about their own attention to, and experience of, the object/event and the general situation.

Individuals whose sensory and movement differences impact their interactions with the environment; awareness of their own physiological states; and capacity for joint attention will clearly be at a significant disadvantage in such tasks.

Deficits in joint attention skills, where they exist, prevent infants from following into and directing other’s attention and interest to objects in their shared world. To demonstrate one consequence of such deficits, Carpenter and Tomasello (2000) cite research in which:

... children with autism did not use the adult’s gaze direction to learn new words, instead learned the new word for the object they themselves were looking at when the word was uttered. Because of the tendency of these children not to use joint attention behaviours to establish reference and because adults occasionally label objects that are not already in the child’s focus of attention, it is not surprising that there are abundant examples of ‘metaphorical speech’ in children with autism. (Carpenter and Tomasello, 2000, p45)

It may be concluded that:

... whereas these children may learn words in scaffolded interactions in which adults follow into their focus of attention, they are less able to do this in less ostensive contexts, when they must determine and use the speaker’s perspective. (Carpenter and Tomasello, 2000, p45)

Note the importance of “*following into*” the autistic child’s focus of attention, rather than expecting the child to follow the adult’s focus. A basic requirement of “message passing” and confrontational testing, on the other hand, is for the subject to be able to do the opposite - “follow in to” the researcher’s focus of attention.

C.13 Executive Functions

Mundy and Stella (2000) characterize “executive functions” as frontally mediated processes whose function is to select appropriate goal-directed actions from an array of competing but context-inappropriate options. Memory, perception, and affective or motivation systems contribute to the choice of action.

As noted in Section C.8, the ability to formulate goals may be impaired in the FC user population by difficulties with sensory modulation and flexible interaction with the environment. Similarly, perceptual abnormalities may lead to weak central coherence and “context-free” processing – clearly problematic for selection of context-appropriate actions. As noted in Section C.11 and C.12, problems with relatedness and joint attention may interfere with an individual’s ability to learn from the goal-oriented behaviour of others.

Koziol, Budding & Chidekel (2011) cite several studies demonstrating a strong relationship between early gross motor problems and later executive cognitive deficits. They suggest that this is because motor acts form the essential framework around which all activity is produced, in a context of continuous sensorimotor interaction with the environment. They therefore characterize executive function as an extension of the motor control system, and implicate the cerebellum in executive function development (see Section C.7). It follows that difficulties with “continuous sensorimotor interaction with the environment” are likely to impact on executive function.

Executive functions include:

- Activation of behaviour and simultaneous inhibition of competing responses. (Mundy and Stella, 2000) Inhibition is described as the ability to stop a well-practiced and “ready” response when that response is not adaptive. (Rogers and Bennetto, 2000)
- Regulation of attention to filter distractions (Mundy and Stella, 2000);
- Shifting attentional focus from one stimulus to another or from one idea to another (Mundy and Stella, 2000). Rogers and Bennetto (2000) note that shifting attention to a second stimulus involves inhibiting attention to the first. Shifting attention facilitates cognitive flexibility, while difficulty shifting results in perseveration of thoughts and actions.
- Uploading and manipulation of mental representations to bring them to bear in a task-effective fashion. (Mundy and Stella, 2000)
- Working memory: Simultaneous processing and storage of information during complex cognitive tasks. This is critical for integrating transient, context-specific information from diverse sources – essential in social interactions. (Rogers and Bennetto, 2000).

Note that executive functions have much in common with the “movement disturbances” targeted in facilitated communication training: initiation; stopping (inhibition); sequencing; continuing; switching; and combining (Remington-Gurney, 2009).

Rogers and Bennetto (2000) observe that executive dysfunction does not present clearly early in autism, although it may be inferred through early deficits in imitation and joint attention.

Joint attention has powerful working memory demands, for the infant must hold on line the partner’s attention focus while seeking to coordinate it with the

infant's own visual experience. There are also powerful inhibition and goal-seeking demands as the infant maintains the goal of shared attention until it is reached while inhibiting responses to other visual distractions. Finally, there are clear set-shifting demands on the infant. (Rogers and Bennetto, 2000, p93.)

As observed by Rogers and Bennetto (2000), interventions that attend to executive difficulties target variables such as increased structure, visual supports for working memory, visual systems for organization, and environmental supports for set shifting to help with transitions and change. This is very reminiscent of the environmental and interactional support and scaffolding that may be provided as part of Facilitated Communication – and which may be extremely difficult to maintain under “controlled conditions” contrived for experiments designed around message passing and confrontational testing.

C.14 Memory

Koziol *et al* (2011) suggest that the brain evolved – not for cognition – but rather for the control of action or movement in continuous interaction with the environment.

For this, it needed sensorimotor “procedural” learning of motor skills, and “action control” mechanisms, to automate and adjust behaviour on the basis of anticipated sensory feedforward and feedback.

It also needed mechanisms that could allow for “off-line” manipulation of action control for the purpose of goal-directed planning and problem solving – “declarative” knowledge.

Koziol *et al* (2011) propose that, in typical development, the sensorimotor information obtained through procedural learning remains available for “off-line” use and manipulation in declarative knowledge.

This blending of declarative and procedural knowledge represents “embodied” cognition, which directly links movement to thought to make semantic memory - memory of facts - possible. Semantic memory provides structure and meaning for episodic memory, which binds facts, events, and experiences together. The authors go on to discuss ways in which their model might predict development of higher cognitive functions such as language processes, communication processes, social cognition and theory of mind.

Although autism is only briefly mentioned in Koziol *et al* (2011), the model does predict memory difficulties for populations characterized by sensory and movement differences.

In a review article, Maras and Bowler (2012) cite evidence that some memory processes (cued recall, priming, recognition, and memory for facts) tend to be intact in autistic individuals, while others (source monitoring, episodic recollection and the recall of personally experienced events) tend to be impaired. This appears to relate to difficulties in processing relations among elements of an experience, and seems consistent with the model proposed by Koziol *et al* (2011).

Episodic events are made up of perceptual, temporal, spatial, semantic and affective elements, which need to be linked together at encoding in a way that differentiates one episode from another. If these components are not sufficiently bound due, for example,

to difficulties in integrating information from different domains – (in line, perhaps, with an under-connectivity account of ASD?) - it may be possible to recall an element without recalling which experience it was from. This may particularly be so if impairments in executive functioning result in difficulties deploying flexible recall strategies. (Maras and Bowler, 2012.)

Maras and Bowler (2012) make the point that the research they cite has been undertaken with “higher functioning” individuals. Although the concepts of high- and low-functioning may be brought into questions by FC, it should be noted that individuals with greater sensory-motor differences are likely to be those commonly identified as low-functioning. Given the model outlined by Koziol *et al* (2011), it seems highly likely that episodic memory may be more severely impacted in individuals with greater sensory-motor issues.

The memory difficulties identified in autism are likely to impact on the way individuals perceive, understand, interpret, and reconstruct the world around them (Maras and Bowler, 2012). Clearly, this is likely to impact on individuals’ ability to recount experiences or exposures to stimuli, as required in message passing and confrontational tests.

C.15 Implications for intervention

Prizant, Wetherby, & Rydell (2000) make the following comment regarding the nature of intervention 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.)

Individuals with severe communication impairments may have considerable difficulty in engaging in interventions compatible with this vision. Augmentative and Alternative Communication strategies are an essential key. The greater capacity the strategy has for novel communication, the more the individual will be able to engage with the world and let the rest of us know who they are. For some individuals, Facilitated Communication as part of a multi-modal communication strategy is their gateway.

Appendix D Evidence based processes

Speech Pathology Australia (SPA) states, in their Clinical Guideline for Augmentative and Alternative Communication (AAC), that SPA:

... supports an evidence based practice approach to the assessment, intervention, and outcome measurement in the provision of AAC and other supports for people with complex communication needs (Speech Pathology Australia, 2012, p.5).

The main body of this submission has examined Facilitated Communication as an evidence based intervention. Appendix D will examine assessment and outcome measures.

D.1 The impact of theoretical background

The existence of two quite different approaches in the FC debate was recognised in the review of FC commissioned by Disability Services Queensland in 2006:

The two approaches are reflected in the type of research done and the research tools used. The antagonists of FC ... have addressed this problem using the standard experimental procedures of the behavioural sciences. The proponents of FC tend to focus on the ... issue of providing the possibility of language-based communication to those who have difficulty in communicating. This group have ... adopted a much broader research agenda ... (Tehan and Senior, 2006, p.6).

Behaviourist approaches generally focus on clearly defined skills, reflecting the “reductionist” belief that complex things can always be reduced to simpler or more fundamental things without loss of meaning. Measurement of success is highly quantitative, with “*frequency counts of the correctness of objectively defined responses as primary evidence of skill development and, ultimately, ‘mastery’ of skills*” (Prizant, Wetherby, Rubin, Laurent, Rydell, 2006, p124). It is undoubtedly easier for someone from a behaviourist background, who sees learning in terms of observable behaviour with no independent significance for cognitive processes, to imagine an experimental design in which the phenomenon being studied is fully reducible – that is, in which all variables and the relationships between them are fully understood, measurable and controllable.

The alternative to “reductionism” is “holism”: “*transformations occur when meanings are added that render ... phenomena unknowable by breaking them into parts and adding them together*” (Poplin, 1995, p.131-2). Social-pragmatic developmental approaches are more holistic, likely to be focused on complex, interrelated phenomenon such as social and emotional development and social communication. The variables, and relationships between variables, in these complex phenomena are likely to be significantly less amenable to objective definition, measurement and modelling. Further, intense collection of frequency counts is unlikely in a social-pragmatic approach, as it is thought to interfere with “*caregivers or therapists establishing a continuous reciprocal flow and affective rhythm*” (Greenspan 2001, p37). As a result, neither the learning process nor the complex benefits that may accrue are fully amenable to quantification.

This is not to suggest that there is no place for quantitative investigations in social-pragmatic research. However, qualitative research is recognised as essential in helping to

unravel the complex processes targeted through social-pragmatic interventions, and in identifying which parts of the phenomenon being studied are most amenable to quantitative research.

Much commentary on FC takes a more simplistic view of the quantitative/ qualitative dichotomy. For example, the Queensland report observes:

There is, undoubtedly, conflicting evidence about the effectiveness of FC but the debate largely comes down to differences of opinion based on controlled/ quantitative studies versus uncontrolled/ qualitative studies. (Mazerole and Legosz, 2012, p70).

Qualitative studies are commonly dismissed as valueless by critics of FC, however this attitude is not consistent with more objective standpoints. As noted in Section 3.3, the word “empirical” means “*based or acting on observation or experiment ...*” (The Australian Concise Oxford Dictionary, 1987, p338). That is, “empirical” embraces data both from controlled experiments and from careful observation under more natural circumstances. What “empirical data” is intended to be free of is prejudice and dogma based on existing “theory”. Unfortunately prejudice and dogma have dominated the FC debate for more than two decades.

D.2 Assessment

Facilitators are instructed in training to “assume competence”. This has been characterized as follows by critics of the strategy:

... in training seminars, and in professional articles (e.g., Biklen, 1990) potential facilitators are instructed not to test communication competence and to assume that the individual with severe disabilities is able to communicate competently. One researcher in the field of autism summarized this perspective:

The ideologues promoting "Facilitated Communication" use an especially pernicious form of sales technique. They claim that "Facilitated Communication" requires faith and a trusting relationship to be effective. They claim that research is inappropriate because it interferes with the trusting relationship (Schopler, 1992, p. 331) (Jacobson, Mulick, & Schwartz, 1995, p758).

It is important to recognize that “assumption of competence” is simply the opposite of imposing eligibility criteria for access to communication services and supports.

Imposition of eligibility criteria violates the principles of AAC practice according to ASHA’s “Position Statement on Access to Communication Services and Supports: Concerns Regarding the Application of Restrictive “Eligibility” Policies”:

... Eligibility determinations based on a priori criteria violate recommended practice principles by precluding consideration of individual needs. These a priori criteria include, but are not limited to: (a) discrepancies between cognitive and communication functioning; (b) chronological age; (c) diagnosis; (d) absence of cognitive or other skills purported to be prerequisites; (e) failure to benefit from previous communication services and supports; (f) restrictive interpretations of educational, vocational, and/or medical necessity; (g) lack of appropriately trained personnel; and (h) lack of adequate funds or other resources (National

Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2003).

In stark contrast to this position, the Queensland reviewers have recommended that FC users should be required to “*demonstrate their skills through robust assessment processes*” (Mazerole and Legosz, 2012, p9). They have endorsed, for “*each and every individual who uses either FC or any AAC option*”, the following assessment process recommended by Emeritus Professor Alan Hudson (Mazerole and Legosz, 2012, p12):

Examination of any documentation about the user: This will include reports of any previous assessments, communication plans, behavior support plans, medical reports etc.

Interviews of individuals who know the user well: This will involve interviewing all of those who have a good knowledge of the user, e.g. carers, family members, other service providers.

The conduct of any specific assessments of the user: This could include cognitive assessment by a psychologist, language assessment by a speech pathologist, eye sight testing by an optometrist, motor skills by an occupational therapist.

The direct observation of the user engaging in everyday activities: These may be routine activities or activities specifically requested by the validation team to observe the use of particular skills.

Controlled testing of the user to communicate using FC: This typically involves activities where information is provided to the user but not the facilitator and then asking the user to repeat that information via the use of FC.

The information gathered from this range of sources is then examined to identify where the evidence converges (Mazerole and Legosz, 2012, p12).

While a thorough understanding of an individual’s background and history may be extremely beneficial in planning their support, ASHA’s position statement makes it clear that neither previous failure, nor assessment of cognitive or other skills purported to be prerequisites, should prejudice an individual’s access to communication services and supports. As noted by ASHA’s “National Joint Committee for the Communication Needs of Persons With Severe Disabilities”:

... so many factors ... may contribute to an individual's perceived failure to benefit from previous communication services and supports that failure cannot be attributed with certainty to the individual alone. These factors may include the selection of inappropriate intervention goals, insufficient instructional time, unsuitable or outdated intervention methods or materials, a failure to collect and analyze meaningful performance data, a failure to incorporate suitable assistive technology, a failure to recognize or address the needs and concerns of culturally/linguistically diverse families, as these might affect participation in communication services; and/or the use of irrelevant or erroneous criteria to evaluate intervention. An individual's perceived failure to benefit also may relate to health, environmental, or other factors that were not adequately considered in previous communication services and support. (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2002).

In particular, please note the reference to “*a failure to collect and analyze meaningful performance data*” and “*the use of irrelevant or erroneous criteria to evaluate intervention*”.

Professor Hudson has proposed that FC users should be asked to “message pass”, that is to repeat information that has been provided to them and not to the facilitator. Please refer to my comments in Section 3.2.1 regarding the suitability of using a task so clearly problematic for a large proportion of the population as a test to validate their communication.

Please also refer to my comments in Section D.3 regarding inappropriate communication assessment tools that have been endorsed by the Queensland reviewers.

With respect to cognitive testing, research has demonstrated:

... that the relationship between language and cognition is neither straightforward nor static (Casby, 1992; Cole & Fey, 1996; Kangas & Lloyd, 1988; Notari, Cole, & Mills, 1992; Rice & Kemper, 1984); that tests purporting to assess cognitive and linguistic performance often measure the same fundamental skills (ASHA, 1999, 2000; Secord, 1992); that assessments typically used for deriving cognitive/language profiles yield sizable variation in discrepancy determinations (Cole, Dale & Mills, 1992); and that children with disabilities whose cognitive and language skills were commensurate nonetheless benefit from language intervention (Cole, Dale, & Mills, 1990). Given the lack of substantiation for cognitive referencing as a prognostic indicator, it should not be used as the basis for restricting access to communication services and supports. (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2002).

The role of “*specific assessments of the user*” by other members of the “*validation team*” is unclear. Optometrists and occupational therapists are mentioned. Involvement by such professionals would be welcomed if their role is to work with the team to help remove barriers to progress and to identify supports and interventions that may assist the user. As observed by ASHA’s National Joint Committee for the Communication Needs of Persons With Severe Disabilities:

... previous experiences should be examined in order to determine ways in which communication services and supports could be better tailored to meet the individual's unique communication needs (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2002).

However, this is not a description of “*validation*”. Inclusion of optometrists and occupational therapists in a team specifically formed to assess the “*validity*” of a person’s access to AAC (including FC) suggests that their role may be to debunk the existence of sensory and motor difficulties that may warrant accommodation through FC. As we have seen, the Queensland reviewers took the following approach to such issues:

The time frame and TOR [Terms of Reference] for this review limited our capacity to examine the research evidence regarding movement disorders and peripheral vision in any detail, but we were swayed by the advice of experts who have studied these fields in great detail and in some cases, are leaders in both research and practice in these fields. (Mazerole and Legosz, 2012, p65).

Please see Appendices A and C, which demonstrate dissonance between the position taken by the reviewers (and their expert advisors) on sensory and motor issues, and that taken by proponents of FC and supported by extensive research. Please also note that more research would be required before the impact and nature of sensory and motor

issues specifically on the FC population are adequately understood. In the absence of adequate research, assessment of candidates for FC is undertaken by appropriately trained professionals using their clinical experience and “best practice” guidelines, fully in line with definitions of EBP as discussed in Section 2.

It seems likely that, in a “validation team”, “*specific assessment of the user*” may be intended to determine whether they have the:

... skill requirements or performance criteria ... necessary for an individual to benefit from communication services or supports (Miller & Chapman, 1980; Shane & Bashir, 1980).

In the past, the goal of such approaches has been clear:

... research linking specific sensorimotor skills to language acquisition in typically-developing children was interpreted as suggesting that such skills are prerequisites for speech and language development in children with severe disabilities. Thus, students not demonstrating these skills were considered ineligible for direct communication services (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2002).

This approach has, however, been discredited:

... research has documented that children and adults who do not demonstrate these supposed prerequisites can benefit from appropriate communication services and supports (Brady & McLean, 2000; Kangas & Lloyd, 1988; McCathren, 2000; Reichle & Yoder, 1985; Ronski & Sevcik, 1996). Thus, access to communication services and supports should not be predicated on the demonstration of skills once considered to be prerequisites (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2002).

As a further comment on the “validation team” proposed by the Queensland review, please note that:

Decisions regarding team composition, types, amounts, and duration of services provided, intervention setting, and service delivery models should be based on the individual's communication needs and preferences (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2003)

That is, it should not be determined by an administrative directive.

Importantly,

... mere involvement of professionals from a variety of disciplines, such as audiology, general and special education, occupational therapy, physical therapy, and speech-language pathology, does not insure their collaboration in providing relevant and necessary support services. The provision of communication services and supports is likely to be compromised if input from any single professional is not adequately synthesized and coordinated with input from the individual, the family, and other professionals (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2002).

SPA has accepted the value of an interdisciplinary team in designing and implementing supports and accommodations for individual with complex communication needs:

In order to achieve the best possible outcomes for people with complex communication needs, speech pathologists support clients using AAC in collaboration with a multiprofessional (multidisciplinary, interdisciplinary, and trans-disciplinary) team using family and person-centred approaches. (SPA, 2012, p11).

It is also promoted by ASHA in their “Position Statement on Access to Communication Services and Supports: Concerns Regarding the Application of Restrictive “Eligibility” Policies”:

Communication services and supports should be evaluated, planned, and provided by an interdisciplinary team with expertise in communication and language form, content, and function, as well as in augmentative and alternative communication (AAC). (National Joint Committee for the Communication Needs of Persons With Severe Disabilities, 2003)

However this is a very different proposition from that suggested by Emeritus Professor Alan Hudson and endorsed by the Queensland reviewers, which is, assembling a team whose only purpose appears to be to establish, on the basis of “*a priori*” criteria, whether or not the individual should be given access to AAC or, more specifically, FC.

D.3 Communication Assessment Tools

The Queensland reviewers have made the following observation:

... as ASHA (2004) notes “there is no standardized battery of tests that comprise an AAC evaluation”. Even though EBP involves knowledge about best practices, knowledge about the client and knowledge about current devices, technology and systems, all of these processes remain informed guesswork to a large extent and “decision making related to AAC interventions for individuals ... is a complex and challenging endeavour”. (Miranda & Iacoco. 2009, p16). To manage this deficit ASHA (2004) recommend the use of the Participation Model (Beukelman & Miranda, 2005), which incorporates the views of parents, teachers and staff etc to identify the users’ current and potential strengths (Mazerole and Legosz, 2012, p96).

This is a highly significant quote, in light of the reviewers’ assertion in Chapter Five of the Queensland review that the process of matching a client to the most appropriate AAC system is more important than the system ultimately chosen.

The Queensland review did not critically evaluate existing approaches to assessment used in DCCS, but instead recommend:

... several communication assessment tools which could be valuable resources for SLPs and allied health workers to assess the effectiveness of any AAC trial with people with CCN. The appropriate use of such tools and the publication of relevant findings could lead to a greater pool of EBP in the future (Mazerole and Legosz, 2012, p47).

Note that pages 45 and 46 of the Queensland report were missing from the version that was briefly made available on the Internet in response to a “Right to Information” request. The discussion of assessment tools appears to have been on these missing pages. The Department advised that the pages had not been published due to a deferral of access under section 37 of the Right to Information Act 2009. Although initially advised that

they would, eventually, be released I have since been told that the entire report has been withdrawn from public access, and that a new “Right to Information” process would be required before release of the pages would be considered.

Although I am, thus, unable to comment on the full discussion of assessment tools, the reviewers have said that:

Many of these tools are based on observational ratings over a period of time made by staff or family who know the clients well with advice and support by a speech pathologist or experienced practitioner (Mazerole and Legosz, 2012, p47).

This description appears consistent with the data collection recommended in FC training. However the review goes on to state:

Two (The Triple C and the FCCS) have been developed and tested in Australia. When deciding upon an assessment tool, it is important to ascertain whether they have been tested appropriately (e.g. for inter-rater reliability) and are valid and reliable. The Australian tools appear to be both. Valid and reliable tools should enable therapists to assess whether there are any changes in the skills and behaviours of their clients over time; an important process in assessing the effectiveness of any AAC or any combination of AACs (Mazerole and Legosz, 2012, p47).

A respected text book makes the following comment regarding choice of appropriate instruments for collecting data:

Validity is the development of sound evidence to demonstrate that the test interpretation (of scores about the concept or construct that the test is assumed to measure) matches its proposed use This definition, in place since 1985, ... shifts the emphasis from "types" of validity to the "evidence" and "use" of the test or instrument (Thorndike, 1997b). ... Validity is the degree to which all of the evidence points to the intended interpretation of test scores for the proposed purpose. Thus, a focus is on the consequences of using the scores from an instrument (Huble & Zumbo, 1996; Messick, 1980) (Creswell, 2002, p159).

Appropriate ways to determine the validity of an instrument include interviews with participants to report what they experienced or were thinking when they completed the instrument: “*evidence based on response process*” (Creswell, 2002, p.162), and consideration of benefits or liabilities - intended or otherwise - that result from using the instrument: “*evidence based on the consequence of testing*” (Creswell, 2002, p.164-165).

A critique of the Triple C checklist of communication competencies by an FC user provides some “*evidence based on response process*”. This makes it clear that the Triple C may not be a valid tool for individuals who have severe movement disorder. Some of the limitations she notes include:

- *it confuses cognition and function.*
 - *it is based on scales designed for infants.*
 - *it doesn't take account of age, functional impairments such as blindness, deafness or quadriplegia, or the effects of medication or depression.*
- The authors have tried to avoid some of these pitfalls ... but ... they have failed (McDonald, undated).*

Regarding “evidence based on the consequences of testing”, Appendix 6 of the Queensland report states:

We were advised by DCCS staff that, although many offices have the Triple C available to reference and use, many SLPs are not using it because they believe it prescribes a level of communicative competence which is based only on observed behaviours and fails to consider a person’s sensory or motor differences. Thus, it is believed that it underestimates or misclassifies the skills of many individuals (Mazerole and Legosz, 2012, page 235).

Appendix 6 also notes:

The Family and Early Childhood teams (FECS) ... at the DCCS support children with a wide variety of diagnoses. They reported to us that this tool is too limited for their use as it has been designed for children with Cerebral Palsy (CP) aged 4-6 years only. Further, they advised that it is unclear how many SLPs would be using this tool specifically for children with CP in this age group (Mazerole and Legosz, 2012, page 237).

These comments suggest that the instruments recommended by the reviewers are unlikely to be appropriate means of gathering practice-based evidence for the FC population.

SPA’s Clinical Guideline for AAC makes the following observations:

The optimal processes for assessment, intervention, and monitoring/evaluating outcomes when providing AAC to people with complex communication needs can be based on principles drawn from the Participation Model (Beukelman & Mirenda, 2005) and Dynamic Assessment (Hasson & Joffe, 2007; Iacono & Caithness, 2009). The Participation Model includes principles for identifying how various AAC systems and options can address current and future needs of people with complex communication needs, with a focus on facilitating their participation within their chosen communities. Dynamic assessment targets the person’s potential for learning rather than the conduct of a static assessment of current skills, and aligns with the principles and philosophy of the Participation Model (Beukelman & Mirenda, 2005) (Speech Pathology Australia, 2012, p.17).

... The ICF (WHO, 2001) and ICF-CY (WHO, 2007) may be used to help guide development of assessment and intervention goals across contexts, promoting the individual’s participation in society (Speech Pathology Australia, 2012, p.17).

Unlike the Triple C and the FCCS, the Participation Model is held in high regard in Queensland and is in regular use by DCCS SLPs working with clients who use AAC, including FC.

The limited usefulness of standardised testing is made explicit in the following observation from Speech Pathology Australia, taken from their position statement: “Evidence Based Speech Pathology Practice for Individuals with Autism Spectrum Disorder”:

Formal assessments of language, including the use of standardised tests ... may be helpful in gauging a child’s development with reference results to age-based norms. However formal assessments of this nature tend to rely on child cooperation and may be of limited use with students with significant intellectual disabilities, as well as those with no functional speech (National Research Council, 2001; Wetherby, Prizant & Shuler, 2003). Formal assessment may also

be of limited use for some individuals with autism because of the largely social-pragmatic nature of the disorder, which is often beyond the scope of these assessments.

As a result, a range of approaches may be appropriate in assessing individuals with autism (Wetherby, Prizant and Schuler, 2003), including formal and informal assessments, observational, and structured and unstructured assessment tasks. In addition, dynamic assessment, in which the speech pathologist assesses an individual's potential for learning rather than his or her static level of performance at a particular point in time (Hasson & Joffe, 2007), may also be appropriate for individuals with autism. Regardless of the tools used, the assessment must account for the individual's skills and difficulties, and fluctuations and differences in these skills and difficulties across a range of contexts and with a variety of communication partners. In addition, the assessment must consider the activity limitations, participation restrictions, and the personal and environmental factors which impact on the individuals functioning (Australian Institute of Health and Welfare, 2003, Filipek, 1999; National Research Council, 2001) (Speech Pathology Australia, 2009, p9).

The SPA Clinical Guideline for AAC notes:

Criterion referenced outcome measures are a viable and effective alternative to standardised tests due to the ability to individualise the target outcome according to the needs, abilities and goals of the person. There are now several evidence-based tools for measuring and describing outcomes for people who use AAC. These tools can be used in the assessment, monitoring, and outcome measurement phases of management. ... [C]linicians need not rely on self-reported or caregiver-reported outcomes only (SPA, 2012, p28).

D.4 Outcome measures

The SPA Clinical Guideline for AAC notes that:

Outcome measurement in the field of AAC has, to date, focused primarily upon 'operational competence' (i.e., skills in access and use of an AAC system or strategy) and 'linguistic competence' (i.e., skills in receiving language through the spoken modality and producing language using the AAC system). ... Successful AAC interventions resulting in better communication can lead to improved personal well-being and quality of life and reduction in behaviours of concern (Sigafoos et al., 2003). Therefore, it is recommended that speech pathology practice includes measurement of outcomes. There is also a need to broaden the scope of measures, in particular, to address the extent to which AAC interventions lead to improved participation in all aspects of daily life. (SPA, 2012, p28)

I am not aware of any quantitative study of FC that focuses on the outcome measures discussed in this quote. Rather, quantitative FC research is almost exclusively designed to measure facilitator influence in tasks based on message passing. This is despite there being no evidence that message passing is a reasonable test for general communicative ability.

Behaviour change and skill development has been described in qualitative FC research, however this has been dismissed by the reviewers as the product of a “confounding factor”, not of improved access to communication.

D.6 Confounding Factor

The following statement appears in a list of three points that the Queensland reviewers believe to be “*indisputable*”:

Although there are some concessions that ‘something’ in the FC environment (a confounding factor) may work for a few clients, there is absolutely no clarification what it is that actually works, in what settings or for whom. Without this vital information it is impossible to identify who might benefit from the intervention and, more importantly, who might suffer some harm from it. However, as discussed in the introduction of this chapter, and later in this report, Queensland may be in a unique position to contribute valuable information to this debate.” (Mazerole and Legosz, 2012, p71).

The reviewers suggest the following as possible candidates for the “confounding factor”:

“... different baseline skills/conditions/diagnoses and other individual differences, different treatment processes such as extra attention during treatment, facilitator influence etc. In other words, there may be alternative explanations for the success of some individuals” (Mazerole and Legosz, 2012, p71).

They also cite a reference to use of FC being accompanied by an effect “*akin to the Hawthorne effect*” (Crossley & Borthwick, 2002, cited in Mazerole and Legosz, 2012, p71). The reviewers define the Hawthorne effect as:

“a methodology artefact in behavioural field experiments arising from the awareness of research participants that they are being studied. This awareness leads them to respond to the social conditions of the data collection process rather than to the experimental treatment the researcher intended to study. ... [T]he artefact ... has widely been considered to be a potential contaminant of field experiments conducted in real-life settings ... (Lewis-Beck, Bryman and Futing Liao, 2004), quoted in Mazerole and Legosz, 2012, p71).

The reviewers call for “*rigorous assessment so that [the] importance [of the Hawthorne effect] in the outcomes of FC users can be identified and accounted for* (Mazerole and Legosz, 2012, p72). That is, in accordance with a view that all things are reducible, they see the Hawthorne effect as an “artefact” or contaminant that must be eliminated before the true impact of FC can be measured.

Yet, the authors of one large literature review which examined a variety of communication based treatments for ASD (excluding FC) are reported in Chapter Five of the Queensland review to have concluded:

“Given the language and social deficits that characterize autism, merely providing a means of communication does not, in and of itself, appear to give the

individual with ASD the ability to communicate” (Brunner and Seung, 2010, cited in Mazerole and Legosz, 2012, p84)

So what is the missing factor, and how integral is it to the success of a communication program for autistic AAC users? Can it really be viewed simply as a “contaminant”?

FC is an access method. It can be used to help individuals make choices – for example between two different types of food.

However, a social-pragmatic developmental approach encourages families and carers to understand normal patterns of language and social development and to create motivating contexts, routines and activities for communication. This enhanced social interaction may open the way for cascading developmental benefits as discussed in Appendix C.

It is noted that 96% of departmental staff, in response to the initial trial of FC in 1992-3, felt that it had not only “*improved their clients’ ability to make their needs known*”, but also that it had “*changed the way they talk to the clients ...*” (Mazerole and Legosz, 2012, p106).

The reviewers also make very brief mention (Mazerole and Legosz, 2012, p129) of an excellent report by the Occupational Therapy Department of the University of Queensland, which collaborated with the DCSS to survey FC users’ and their families’ perceptions of the impact of FC on their lives. The study concluded that “*When using FCT, people were able to demonstrate competence, convey what they knew, and express how they felt. As a result, families had a more positive perception of them*” (de Jonge, de Souza, Carlson, Wilson, in press).

What is likely to happen if the benefits of enhanced social interaction are “controlled for”? Something similar can probably be seen in situations where FC has been introduced but not appropriately supported. As described in the following quote from the review:

FC is an AAC and therefore susceptible to the same factors that influence outcomes in conventional AAC programs such as staff training needs, staff turnover lack of resources for communication opportunities and low prioritisation of the consumer’s right to communicate. (Remington Gurnery, 1996, p6, quoted in Mazerole and Legosz, 2012, p112).

As we have seen in Section D.1, a social-pragmatic view of FC accepts complexity, and is likely to embrace something “*akin to the Hawthorne effect*” as part of the learning process – not a contaminant. Such an approach places emphasis on addressing the learner’s communication development within the context of developing relationships and social-emotional growth. Emphasis is also placed on understanding and expressing emotions and on mastering increasingly complex stages of emotional and social-cognitive development (Prizant and Wetherby, 1998). While FC is merely an access strategy, enhanced communication within a socially rich environment may enable

cognitive and emotional development along the pathways identified by social-pragmatists, even if this process is not intentionally targeted by carers and therapists.

Behaviourist approaches may, on the other hand, minimize the role of social engagement, affect, and emotional expression. An illustration of this comes from the author of two of the “systematic reviews” of FC reported by Mazerole and Legosz (2012, pp49-50):

Might we also arrange for the child to have as many enjoyable experiences as possible? ... Sure. But if any of these adjunct therapies jeopardized the chances for the main treatment to work, even if only by taking time away from it, would we subject the child to the adjunct therapy? Hopefully not. (Green, 1996, p27, quoted in Prizant and Wetherby, 1998, p343).

Contemporary interventions are unlikely to follow strictly behaviourist or social-pragmatic extremes, but instead will be hybrids. As noted in 2005:

“Ideologies are useful theoretically to help us devise diverse strategies and practices, but lethal when they become prisons to our thinking and acting with children.” (Poplin and Rogers, 2005, pp.159-160)

The same commentator also gives an insight into a phenomenon which may explain the “confounding factor”. She notes that holistic approaches to intervention (such as social pragmatism) cannot completely avoid reductionism when specific skills need to be taught. However, the reductionist approaches – explicit teaching of skills - must be incorporated into a whole-part-whole sequence of learning which can also be described as “romance-precision-wisdom”. This suggests that in the beginning there is a whole picture, a sense of something new and intriguing to be understood. The attraction to understand it – the “romance” – inspires the learner to address the specific skills or “reduced” parts that are needed to master – to “construct” - the whole task. Thus, the skills or parts that must be reduced always remain connected to the larger picture, and once the precision is mastered the learner moves beyond the conscious, diligent attention to parts and skills to a stage of wisdom, empowered by the new knowledge (Poplin, 1995, p132-3).

Conversely, reductionist practices may be characterised simply as “part-whole” sequences, in which instructors teach isolates skills not because the student is motivated to learn them, but because someone else has determined they should. Presentation of learning out of context and out of the natural whole-part-whole sequence lacks intrinsic reward and disconnects the task from the student’s broader interests in life (Poplin, 1995, p132-3). Further, drilling on things that can be reduced does not automatically lead students to connect these small skills to anything they already know, while there is danger of neglecting things that cannot be reduced, such as purpose, justice, ethics, goodness, sacrifice, and commitment (Poplin and Rogers, 2005).

“Romance-precision-wisdom” can, perhaps, be seen in action in the increasing number of anecdotal reports of autistic individuals who demonstrate “unexpected skills” when exposed to iPads. The technology is so attractive; it seems some individuals are highly motivated to engage with it. Once engaged all manner of training can follow - but the initial breakthrough came because they were able to use the technology immediately, to pursue comparatively complex and satisfying activities that were meaningful to them.

Perhaps the basics of copy-typing or a program such as PECS may be taught through a more painstaking, bottom-up approach - but the immediate, intrinsic rewards are not available. Learners may not even see the connection between these skills and meaningful, personal communication.

The skill of individuals who can access an iPad independently is not questioned - even if it was “unexpected”. FC seeks to put similarly motivating learning and communication opportunities into hands that could not otherwise access them, by addressing movement differences and other support needs. It is interesting to speculate on the additional value a relationship with a communication partner may provide, in comparison with an unmediated relationship with technology that may interfere with social engagement.

Appendix E: Alleged harms caused by use of FC.

The SPA Clinical Guideline for AACs states:

Harms associated with FC pertain to its potential to remove a person's communication rights (...see UNCRPD, 2006), any negative consequences of the constructed messages not reflecting their own views ..., and indirect harm by replacing time and other resources that could be spent on effective interventions The uncertain authenticity of communication is central to cases involving allegations of abuse ... and disputes over guardianship, or other decisions. (SPA, 2012, p31).

Appendix E examines some of these issues

E.1 Removal of communication rights

The suggestion that individuals' communication rights are best served by restricting the strategies professional clinicians are allowed to offer them is ludicrous.

Article 21 of the UN Convention on the Rights of Persons with Disabilities reads, in part, as follows:

Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by ...:(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions ... (UN General Assembly 2007)

SPA clinical guidelines state:

... communication ... is recognised as a human right (see UNCRPD 2006, Articles, 16, 17, 21, 24). Therefore, people with complex communication needs should not be denied the opportunity to communicate to the best of their ability and in their preferred mode or modalities that reflect their authentic voice (Speech Pathology Australia, 2012, p.12).

Similarly:

The UNCRPD (2006) ... underpins decisions relating to AAC services. (Speech Pathology Australia, 2012, p.30).

Chapter Nine of the Queensland review discusses the policy framework developed by DCCS in 2005 and which, as we have been repeatedly advised, remains in place. This is based on two documents: “*Facilitated Communication Procedures (DSQ 2005a)* and the overarching “*Communication Support for People with Complex Communication Needs*” (DSQ 2005b). The reviewers state that:

The policy aimed to ... affirm the right of people with a disability who have CCN to have an effective communication systems and to develop and use communication skills in their daily lives” (Mazerole and Legosz, 2012, p21)

The reviewers have recognized this in their Executive Summary:

Although we acknowledge the rights of people with disabilities to exercise their right to freedom of expression and opinion through all forms of communication of their choice (Article 21 of the UN Convention on the Rights of Persons with Disabilities), there is also a need for appropriate measures to protect people with disabilities from all forms of exploitation, violence and abuse. This protection includes the need to ensure that all facilities and programs designed to serve persons with disabilities are effectively monitored by independent authorities (Article 16) (Mazerole and Legosz, 2012, p6).

Regarding the reviewers' qualifying comment – that programs designed to serve persons with disabilities must be effectively monitored - please note that failure of oversight does not constitute failure of the strategy of FC. The Departmental Guidelines and Best Practice taught through facilitator training in Queensland meet these concerns if appropriately applied. The Department has not met its own guidelines.

The reviewers go on to assert:

... We believe that this concept also includes the assurance that people with disabilities will only be exposed to interventions that have a strong evidence base and will not be exposed to those that cause harm, or have been identified as high risk (Mazerole and Legosz, 2012, p6).

As established in Chapter Five of the review report, almost no AAC strategies have a strong evidence base. Despite this, the reviewers have made the following comment:

... a combination of the strong endorsement by Speech Pathology Australia (SPA) for evidence based practices (EBP) for all speech and language pathologists (SLP), and emerging research evidence which suggests that AAC systems (not FC) can be effective and not harmful to those who use them, provides support for the department's investment in a diverse range of AAC options, as well as its current policy position (Mazerole and Legosz, 2012, p6).

Once again, FC has been singled out for special consideration. This submission has argued that such treatment is not warranted, as the evidence cited against FC is not credible.

Regarding the risk of harm, the Queensland reviewers have stated in the "Executive Summary" that:

If the department does not agree to phase out FC, its current policies and procedures relating to FC only require minor modification. As discussed in Chapter 9 ... 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).

Similarly:

The policies and practices surrounding individual FC users will be vital for ensuring their safety and integrity (Mazerole and Legosz, 2012, p73).

We contend that the Departmental Guidelines and Best Practice principles meet these concerns if appropriately applied. The Queensland review has made it clear that guidelines and principles are not properly applied.

It is none-the-less important to recognise most facilitated communications are neither controversial nor life-changing. Please see Section 3.1.4: “Is authorship the right question”.

The following extract from SPA’s Clinical Guidelines makes it clear that all AAC systems are not equal in terms of serving an individual’s communication rights:

*The goals of AAC interventions are ... related to developing not only linguistic competence, but also strategic, social, and operational competence (Light, 1989). Linguistic competence includes the acquisition of both spoken and written language skills. The development of literacy skills in both reading and writing is critical for all individuals, but it is especially important for those who use AAC with symbolic understanding (see Smith, 2003). The symbols provided in AAC systems may enable individuals with complex communication needs to communicate a wide variety of messages, however, **the alphabet is the only symbol set that allows precise communication and unlimited message generation** (Erickson & Clendon, 2009). Literacy skills also provide individuals with the independence to govern their program of interventions and maintain their own AAC systems. Individuals who use AAC will be at different places on the continuum of literacy learning (Erickson & Clendon, 2009; Light & McNaughton, 2009). Some will be emerging in their literacy; others will be able to read and write conventionally. Interventions should be appropriate for individuals' literacy levels as determined by a comprehensive assessment. It should also be noted that for individuals who have not developed literacy will require access to and support in using limited message sets (Speech Pathology Australia, 2012, p.25-6. Emphasis added).*

Compare the developmental vision of communication training expressed by SPA in the preceding paragraph with the findings of a 2008 systematic review of AACs other than FC (including PECS, sign, and speech generating devices) reported by Mazerole and Legosz:

The authors concluded that although AAC interventions do not appear to impede speech production, the modest gains observed require realistic expectations among clinicians and other stakeholders (Mazerole and Legosz, 2012, p88)

Similarly:

[Tincani and Devis, 2010] concluded that although ... single-participant data are supportive of PECS as an AAC, to establish mands, the utility of PECS in promoting more advanced communication skills, including tacts (i.e. expressive labels) and intraverbals (i.e. conversation) has not been established. They also noted that ... the majority of participants ... mastered only up to Phases I, II or III ... (Mazerole and Legosz, 2012, p.90)

Mazerole and Legosz (2012) make reference to features of an ideal AAC system:

- *Enables the individual to express a full range of communication functions.*
- *Is compatible with other aspects of the individual’s life.*
- *Considers needs and communication patterns of conversation partners.*
- *Is usable in all environments and physical positions.*
- *Does not restrict the topic or the scope of communication.*
- *Enhances the effectiveness of the individual’s communication.*

- *Allows and fosters continuous growth in the individual's linguistic and related skills.*
 - *Is acceptable and motivating for the individual and significant others.*
 - *Is affordable.*
 - *Is easily maintained and repaired.*
- (Quist and Lloyd, 1997, cited in Mazerole and Legosz, 2012, p.97)*

They do not, however, attempt to examine any of the systems they discuss – for example, PECS and sign language - against these features.

The limitations of systems that offer limited vocabulary, tense, semantic and pragmatic markers, and repair strategies must be acknowledged.

It is accepted that more complex systems will not suit all AAC users – however, as the reviewers note, “*as the user develops their communication systems will also need to change*” (Mazerole and Legosz, 2012, p96).

An individual who may be a candidate for FC is one who has:

... complex communication need [and] who has had little or no success with conventional AAC strategies or techniques and for whom people consider to be untapped potential (Remington Gurney, 2009, p9).

As this paper has shown that research discrediting FC is not itself creditable, individuals such as these should not be denied access to communication simply because an administrative decision has limited options available to professional clinicians.

E.2 Indirect harm by replacing time and other resources that could be spent on effective interventions.

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.

It is recognised that a hybrid approach to an individual's support may make it difficult for researchers to attribute success to one or other component of their program. **This, however, is a problem for researchers to address. It should not be a consideration in designing the optimal program for individuals with complex communication needs.** Please see Appendix D, Section D.2, regarding evidence-based assessment.

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. Current research, discussed in Appendix C, suggests that such activities may have cascading effects on individuals' cognitive development.

FC is 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.

E.3 Decision Making

I have seen no research on the proportion of facilitated communications that lead to disputes, however in view of the amount of facilitated communication that occurs, disputes could only represent a miniscule proportion of total communications.

Any suggestion that the challenge of dealing with disputes outweighs the benefits of improved communication must be examined very closely. The lives of many FC users have been transformed through access to this strategy. (See de Jonge, de Souza, Carlson, Wilson, in press).

It must be recognised that, 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 has been shown to very dramatically reduce challenging behaviour and increase self-determination.

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 facilitated communication.

In Queensland, the DCSS policy framework and FCT training include a very detailed protocol outlining how to respond to controversial or life-changing communication, based on over twenty years of experience and practice in the field. This protocol cannot resolve all the issues that may arise, but it does provide a road-map that may be used to navigate these rare, but difficult situations.

The Queensland review recommended that:

*FC should only be used to indicate an individual's decision if their communication has been validated by robust measures **prior** to making any sensitive or life changing decisions. The Research Team endorses a comprehensive assessment approach such as the one suggested by Professor Hudson. (Mazerole and Legosz, 2012, p9).*

Please see Appendix D, Section D.2, regarding the assessment approach recommended by Professor Hudson.

This – like so many of the reviewer’s attitudes to FC – is quite different from their recommendations regarding AACs other than FC. They have noted in Chapter Five: *Several cognitive, communication and language skills, while not considered prerequisites to AAC, have been found to predict success in AAC programs (ASHA 2004). One construct that appears especially useful is self-determination, or the ability to make decisions about matters affecting one’s life. Therefore ASHA encourages SLPs to involve both individuals who use AAC and their significant others in all phases and aspects of AAC programs (Mazerole and Legosz, 2012, p97).*

This quote makes it clear that individuals who have complex communication needs must be involved in decision-making if they are to develop the ability to make decisions. The quote thus implies that they should not be asked to prove their skill level first. It must be recognised that individuals whose sensory and movement issues are severe, including FC users, may not be able to participate in decision-making without support. Their inability to indicate preferences may have been taken as a lack of preference. In some settings may never have been asked to make any decisions, but merely have been expected to comply with decisions made for them.

E.4 Abuse allegations

The Queensland review quotes Disability Services Queensland’s “Practical Guidelines for Communication Support” to state that:

... people with CCN are more vulnerable to abuse, assault and neglect than other people with a disability, and also less able to report incidents and receive appropriate support. (Disability Services Queensland, 2006, paraphrased in Mazerole and Legosz, 2012, pp16-7).

The reviewers do not discuss the research on which this statement is based. As I have been unable to gain access to the policy document referred to by the reviewers, I am unable to comment on whether any research was cited in that document to support the statement. Research is, however, available: Although by no means a comprehensive review of the literature, the following illustrate this point:

- 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 for 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.

SPA’s clinical guidelines recognise 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 to outstrip concerns about their accuracy. This is illustrated by the Queensland reviewers' statement that allegations reported in the media:

*... generated adverse publicity for FC, severe negative consequences for the families involved, and became a critical issue for professionals subject to mandatory reporting processes. **Consequently**, FC had been discredited in the eyes of most scientists and professional organisations by the late 1990s ... (Mazerole and Legosz, 2012, p19 – emphasis added).*

Similarly, with reference to Queensland, the reviewers state that:

Concerns have also been raised about the possible mistreatment of individual FC users in Queensland which has resulted in legal intervention, and various complaints have been lodged against past and present staff members in the context of these concerns. Indeed, the overall situation in Queensland has caused much anxiety and distress and appears to have exacerbated the polarity of views about FC, which appear to have been extreme (Mazerole and Legosz, 2012, p23).

Is it really being suggesting that people should not be given the means to communicate in case they say something controversial?

As discussed in Section E.3, Queensland has a well-developed protocol for dealing with controversial and life changing communications. The Departmental Policy is outlined in the *Practice Guide: responding to sensitive or life changing information communicated by methods other than speech*. Although the reviewers do not comment directly on this document in their chapter on Departmental policy (Chapter Nine), their conclusion regarding the *Facilitated Communication Procedures* (DSQ, 2005a) is 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).

It must 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.

Risk management requires consideration of potential consequences, and the likelihood of adverse effects. I have been advised by people who have observed FC since its introduction to Queensland that the Department initially used Facilitated Communication in an environment where risk was controlled. Over time poor compliance with protocols identified in Departmental policy increased the risk of bad practice. Statistics on numbers of FC users and facilitators were not kept after 1996, and no attempts were made to monitor numbers of facilitators at each of the four levels of training. As a consequence,

accreditation of the Departmental training package was not renewed. The likelihood of risk to all stakeholders steadily increased. Despite efforts to improve the Department's performance in 2005-6, implementation of Departmental policy has remained inadequate, as described in Chapters Six and Seven of the Queensland review.

Appendix F: Research Recommendations, ASHA, 1994

The following research recommendations have been copied in full from American Speech-Language-Hearing Association. (1994). *Facilitated communication* [Technical Report]. Available from <http://www.asha.org/policy/TR1994-00139.htm>. I have altered the original formatting only by inserting “bullets” to separate different research topics.

Continued research is essential in light of the various concerns that have arisen in relation to facilitated communication. Some areas to pursue are discussed below.

- ***Further research must address the questions of message authorship and validation, with particular emphasis on understanding or confirming communicators' lack of success in experimental validation studies to date. It must be determined to what extent these failures are representative of communicators' abilities to communicate outside experimental settings vs. artifacts of testing in contrived situations.***
- ***Assessment protocols should be designed with particular attention to internal validity.***
- ***Researchers in the experimental and qualitative traditions are encouraged to collaborate in order to design valid, mutually agreed-on procedures for probing validation. Also, individuals and groups must ask themselves what types and amounts of evidence are necessary in order to accept results of validation testing, and then act accordingly.***
- ***Further descriptive research examining the communication process that takes place during facilitated communication is warranted. Studies might examine the facilitator-communicator dyad in facilitated communication, and compare this to other methods of AAC and spoken communication. Such research might also be helpful in delineating the qualities of “good” facilitators. Once again, such a determination will depend on researchers' definitions of facilitated communication and successful outcomes, and their choice of methodology.***
- ***An area of particular interest concerns the methods by which facilitators may inadvertently cue communicators during message transmission, resulting in authorship by facilitators. How can we explain the facts that (a) influence occurs without facilitators' awareness, and, (b) communicators who may have been relatively uninfluenced by prompts and cues during previous forms of instruction are able to act in response to such subtle resistance from facilitators?***
- ***Are there ways of providing feedback to facilitators, through instruction, to advise them when they are inadvertently influencing communicators by leading them to particular locations on letter boards and other visual displays?***
- ***Research detailing changes that occur in people's lives following the introduction of facilitated communication, in terms of communication, behavioral, lifestyle, medical and financial changes, and so forth would be useful. As indicated earlier, the direction (positive and/or negative) and longevity of such changes are critical questions. It may also be of interest to examine the impact of validation testing, relative to the outcomes of such testing on facilitators', communicators' and others' lives.***
- ***Detailed subject descriptions are necessary, regardless of which research methodology is chosen, if we are to begin to differentiate which persons could be most helped by facilitated communication. Minimally, information should be provided about subjects' language and communication abilities, prognosis for speech, previous medical and educational diagnoses (and the basis for such diagnoses), previous communication training and its effectiveness, previous***

literacy training and its effectiveness, and education. Descriptions of facilitators' training and experiences, and the duration and manner in which facilitated communication was introduced and progressed would also be helpful in interpreting and generalizing from the results of future investigations.

- *Based on the apparent success of facilitated communication with some individuals, questions have been raised regarding the validity of previous research and knowledge about autism and related disabilities. For example, some authors have stated that autism should no longer be viewed as a disability that primarily affects social relatedness and communication knowledge and skills, a position currently accepted as the core symptoms of the syndrome (APA, 1994).*
- ***If classic descriptions of autism and other types of disability are inaccurate, it is critical that they be modified based on new empirical data.** For example, what support is there for the central hypothesis on which facilitated communication rests (Biklen, 1993): that its users, and people with autism in general, are impaired in movement rather than social cognition and social relatedness? To advance such a hypothesis in the absence of supporting data is premature at best, and certainly not useful in efforts to develop appropriate services and supports for individuals with severe disabilities. This hypothesis has been offered without addressing persons with autism who are better able to communicate through speech, and whose primary difficulties appear to be in the areas of social cognition and relatedness rather than movement.*
- *Definitions of what constitutes success with facilitated communication vary from one investigator to the next and one facilitator to the next. When the definition of success goes beyond communication to include changes in attending, on-task behavior, others' perceptions of individuals, decreased incidents of challenging behavior, and so forth, we may be comparing different phenomena as we attempt to reconcile differences in results across investigations as well as different interpretations of the same investigation. **Researchers need to be explicit in stating how they define and measure success.***
- ***Research should address both successes and failures in the use of facilitated communication.** The conditions under which each result is achieved should be described in detail.*

Source: ASHA 1994

References

- Adams, L. (1998). Oral-motor and motor-speech characteristics of children with autism. *Focus on Autism and Other Developmental Disabilities*, 13, 108–112.
- Akshoomoff, N (2000) 'Neurological underpinnings of autism', in AM Wetherby & BM Prizant (eds.), *Autism Spectrum Disorders: A Transactional Developmental Perspective*, Paul H. Brookes, Baltimore, MD.
- Alpern, M. (1972). Rod vision(Rod vision chemistry in terms of rhodopsin, visual cycle and pigment-vision relations, considering dark and light adaptation). *The assessment of visual function.*(A 73-16476 05-04) St. Louis, Mo., C. V. Mosby Co., 1972,, 59-82.
- American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders: DSM-IV*. Washington, DC: Author.
- American Psychological Association (2005) *Report of the 2005 Presidential Task Force on Evidence-Based Practice*, Accessed from <https://www.apa.org/practice/resources/evidence/evidence-based-report.pdf> 8.2.14
- American Speech-Language-Hearing Association (1994). Facilitated Communication [Technical Report], <http://www.asha.org/policy/TR1994-00139.htm>, accessed on 31.5.12.
- American Speech-Language-Hearing Association. (1999). IDEA and your caseload: A template for eligibility and dismissal criteria for students 3–21. Rockville, MD: Author.
- American Speech-Language-Hearing Association. (2000). Special Interest Division 1: Language Learning and Education Newsletter, 7(1), 3–29.
- American Speech-Language-Hearing Association (2004). Roles and responsibilities of speech language pathologists with respect to augmentative and alternative communication: technical report. At <http://www.asha.org/docs/html/TR2004-00262.html>.
- American Speech-Language-Hearing Association (ASHA). (2005). *Evidence-Based Practice in Communication Disorders: Position Statement*. At: <http://www.asha.org/docs/pdf/PS2005-00221.pdf>, accessed 4.9.13.
- Anzalone, ME & Williamson, GG (2000) 'Sensory processing and motor performance in autistic spectrum disorders', in AM Wetherby & BM Prizant (eds.), *Autism Spectrum Disorders: A Transactional Developmental Perspective*, Paul H. Brookes, Baltimore, MD.
- Asperger, H. (1944). Die autistischen psychopathen im kindesalter [Autistic psychopathy in childhood]. *Archiv fur Psychatrie und Nervenkrankheiten* 117, 76–136. Translated by Uta Frith and published in U. Frith (Ed.), *Autism and Asperger's Syndrome* (pp. 37–92). Cambridge: Cambridge University Press.

Australian Institute of Health and Welfare (AIHW) (2003). ICF Australian User Guide. Version 1.0. Disability Series. AIHW Cat. No. DIS 33. Canberra: AIHW.

Ayres, AJ (1985) *Development of apraxia and adult onset apraxia*. Sensory Integration International, Torrance: CA.

Baker, AEZ Lane, A Angley, MT & Young, RL (2007) 'The Relationship Between Sensory Processing Patterns and Behaviour Responsiveness in Autistic Disorder', *J. Autism Dev. Disord.* Vol. 38, pp. 867-875.

Baranek, G. T., Parham, L. D., & Bodfish, J. W. (2005). Sensory and motor features in autism: Assessment and intervention. In F. Volkmar, A. Klin, & R. Paul (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., pp. 831–857). Hoboken, NJ: John Wiley & Sons.

Beamish, W (2006) *Positive Behaviour Support – Study Guide*, Brisbane. Digitization and Distribution, Griffith University.

Bebko, JM Perry, A & Bryson, S (1996) 'Multiple method validation study of facilitated communication: II. Individual differences and subgroups results.' *Journal of Autism and Developmental Disorders*, Vol. 26, pp. 19–42.

Bebko, J. M., Perry, A., & Bryson, S. (2003). Commentary: Bebko, Perry, and Bryson on Mostert (2001), "Facilitated Communication Since 1995". *Journal of autism and developmental disorders*, 33(2), 219-220.

Beck, AR & Pirovano, CM (1996) 'Facilitated communicators' performance on a task of receptive language', *Journal of Autism and Developmental Disorders*, Vol. 26, pp. 497–512.

Berkeley, S. L., Zittel, L. L., Pitney, L. V., & Nichols, S. E. (2001). Locomotor and object control skills of children diagnosed with autism. *APAQ*, 18(4).

Bernardi, L & Tuzzi, A (2011a) 'Statistical Analysis of Textual Data from Corpora of Written Communication – New Results from an Italian Interdisciplinary Research Program (EASIEST)', in MR Mohammadi (ed), *A comprehensive book on Autism Spectrum Disorder*, InTech, Rijeke, Croatia.

Bernardi, L & Tuzzi, A (2011b) 'Analyzing Written Communication in AAC Contexts: A Statistical Perspective', *Augmentative and Alternative Communication*, Vol. 27(3), pp. 183-194.

Beukelman, D & Mirenda, P (1998) *Augmentative and alternative communication: Management of severe communication disorders in children and adults*, Baltimore: Paul H. Brookes.

Beukelman DR & Mirenda P, 2005, *Augmentative and alternative communication: Supporting children and adults with complex communication needs*. 3rd edition. Baltimore (MD): Paul H Brookes Publishing Company.

- Biklen, D. (1990). Communication unbound; Autism and praxis, *Harvard Education Review*, 60(3) 291-314.
- Biklen, D (1992) 'Autism orthodoxy versus free speech: A reply to Cummins and Prior', *Harvard Educational Review*, Vol. 62, pp. 242-256.
- Biklen, D. (1993). *Communication unbound: How facilitated communication is challenging traditional views of autism and ability-disability*. New York: Teachers College Press.
- Biklen, D (2005) *Autism and the myth of the person alone*, Cambridge, Eng: University Press.
- Biklen, D & Burke, J (2006) 'Presuming Competence', *Equity & Excellence in Education*, Vol. 39:2, pp. 166-175
- Biklen, D & Duchan, JF (1994) '“I am intelligent:” The social construction of mental retardation', *Journal of the Association for People with Severe Handicaps*, Vol. 19, pp. 173–184.
- Biklen, D Saha, N & Kliwer, C (1995) 'How teachers confirm the authorship of facilitated communication: A portfolio approach', *Journal of the Association for People with Severe Handicaps*, Vol. 20, pp. 45–56.
- Bodfish, J., Symons, F., Parker, D., & Lewis, M. (2000). Varieties of repetitive behavior in autism: Comparisons to mental retardation. *Journal of Autism and Developmental Disorders*, 30, 237–243.
- Bomba, C O'Donnell, L Markowitz, C & Holmes, DL (1996) 'Evaluating the impact of facilitated communication on the communicative competence of fourteen students with autism', *Journal of Autism and Developmental Disorders*, Vol. 26, pp. 43–58.
- Bondy, A & Frost, L (1994) The Picture Exchange Communication System. *Focus on Autistic Behaviour*, 9,1-19.
- Bornman, J & Bryen, DN. (2013) Social Validation of Vocabulary Selection: Ensuring Stakeholder Relevance. *Augmentative and Alternative Communication*, 29(2): 174–181.
- Brady, N. C., & McLean, L. K. (2000). Emergent symbolic relations in speakers and nonspeakers. *Research in Developmental Disabilities*, 21, 197–214.
- Brunner DL & Seung HK (2009) Evaluation of the efficacy of communication –based treatments for autism spectrum disorders, *Communication Disorders Quarterly*, 31, 15-41.
- Bryen, D. N. & Wickman, C. H. (2011). Ending the silence of people with little or no functional speech: Testifying in court. *Disability Studies Quarterly*. 31(4). Retrieved from: <http://dsqsds.org/article/view/1711>.
- Burgoine, E., & Wing, L. (1983). Identical triplets with Asperger's syndrome. *The British Journal of Psychiatry*, 143(3), 261-265.

Cabay, M (1994) 'A controlled evaluation of facilitated communication with four autistic children', *Journal of Autism and Developmental Disorders*, Vol. 24, pp. 517-527.

Calculator, SN & Hatch, ER (1995) 'Validation of facilitated communication: A case study and beyond.' *American Journal of Speech-Language Pathology*, Vol. 4, pp. 49-58.

Calculator, S & Singer, K (1992) 'Letter to the editor: Preliminary validation of facilitated communication', *Topics in Language Disorders*, Vol. 13(1), pp. ix-xvi,

Cardinal, DN Hanson, D & Wakeham, J (1996) 'Investigation of authorship in facilitated communication', *Mental Retardation*, Vol. 34, pp. 231-242.

Carpenter, M & Tomasello, M (2000) 'Joint attention, cultural learning, and language acquisition: Implications for children with autism', in AM Wetherby & BM Prizant (eds.), *Autism Spectrum Disorders: A Transactional Developmental Perspective*, Paul H. Brookes, Baltimore, MD.

Casanova, M. November 2012, Personal answer to question in AWARES online conference, *Autism 2012*, <http://www.awares.org/conferences/default.asp>.

Casby, M. W. (1992). The cognitive hypothesis and its influence on speech-language services in schools. *Language, Speech, and Hearing Services in Schools*, 23, 198-202.

Clark, J. M., & Paivio, A. (1991). Dual coding theory and education. *Educational psychology review*, 3(3), 149-210

Clarkson, G (1994) 'Creative music therapy and facilitated communication: New ways of reaching students with autism'. *Preventing School Failure*, Vol. 28, pp. 31-33.

Close, D & Horner, R (1999) 'Architectural design in positive behavioural support' in J. Scotti & L. Meyer (eds.), *Behavioural intervention: Principals, models, and practices* (pp. 251-266). Baltimore: Paul H. Brookes.

Cole, K. N., Dale, P. S., & Mills, P. E. (1990). Defining language delay in young children by cognitive referencing: Are we saying more than we know? *Applied Psycholinguistics*, 11, 291-302.

Cole, K. N., Dale, P. S., & Mills, P. E. (1992). Stability of the intelligence quotient-language quotient relation: Is discrepancy modeling based on myth? *American Journal of Mental Retardation*, 97(2), 131-145.

Cole, K. N., & Fey, M. E. (1996). Cognitive referencing in language assessment. In K. N. Cole, P. S. Dale, & D. J. Thal (Eds.), *Assessment of communication and language* (pp. 143-159). Baltimore: Brookes.

Creswell, J. (2002) *Educational Research: Planning, Conducting, and Evaluating Quantitative and Qualitative Research*, Pearson, Boston [Fourth Edition].

Crews, WD Sanders, EC Hensley, LG Johnson, YM Bonaventura, S Rhodes, RD & Garren, MP (1995) 'An evaluation of facilitated communication in a group of nonverbal

individuals with mental retardation', *Journal of Autism and Developmental Disorders*, Vol. 25, pp.205–213.

Crossley, R (1992) 'Who said that?' In DEAL Communication Centre (Ed.), *Facilitated communication training* (pp. 42-54). Caulfield, VA (Australia).

Crossley, R (1994) *Facilitated Communication Training*, Teachers College Press, New York.

Crossley R & Borthwick C (2002) *What constitutes evidence? Why the debate about facilitated communication is important for ISAAC*. Paper written for the proceedings of the Seventh Biennial ISAAC Research Symposium, Odense, Denmark, August 2002.

Crossley, R & Chadwick, M: 'Facilitated Communication Outcomes' ISAAC (2000) http://www.mamre.org.au/articles/2007/09/07/Facilitated_Communication_Outcomes.pdf

Cummins, RA & Prior, MP (1992) 'Autism and assisted communication: A response to Biklen', *Harvard Educational Review*, Vol. 62, pp.228–241.

Dawson, G & Watling, R (2000) 'Interventions to facilitate auditory, visual, and motor integration in autism: A review of the evidence', *Journal of Autism and Developmental Disorders*, Vol. 30, pp. 415–421.

Disability Services Queensland (DSQ) (2005a) *Facilitated Communication Procedures*.

Disability Services Queensland (DSQ), 2005b, *Practice Guidelines: Communication Support for People with Complex Communication Needs: Community and Specialist Services*.

Disability Services Queensland (DSQ) (2006) *Practical Guidelines for Communication Support*.

de Jonge, D de Souza, N Carlson, G Wilson, M (in press), 'Facilitated Communication Training: Exploration of perceptions of ability and reducing physical support', *Disability Studies Quarterly*.

Dewey, D (1995) 'What is Developmental Dyspraxia?' *Brain and Cognition*, Vol. 29, pp.254-274.

Donnellan, AM Sabin, LA, & Majure, LA (1992) 'Facilitated communication: Beyond the quandary to the questions' *Topics in Language Disorders*, Vol. 12, pp. 69–82.

Dowden P and Cook A (2002) *Choosing effective selection techniques for beginning communicators*. In J Reichle, D Beukelman, J Light, *Implementing an augmentative communication system: exemplary strategies for beginning communicators*. Baltimore, MD: Paul H. Brookes Publishing Co.

Dyck, M., & Piek, J., & Hay, D., & Hallmayer, J. (2007). The relationship between symptoms and abilities in autism. *Journal of Developmental and Physical Disabilities*, 19, 251–261.

Dziuk, M. A., Larson, J. C., Apostu, A., Mahone, E. M., Denckla, M. B., & Mostofsky, S. H. (2007). Dyspraxia in autism: association with motor, social, and communicative deficits. *Developmental Medicine & Child Neurology*, 49(10), 734-739.

Eberlin, M, McConnachie, G, Ibel, S & Volpe, L (1993) 'Facilitated communication: A failure to replicate the phenomenon', *Journal of Autism and Developmental Disorders*, Vol. 23, pp. 507-530.

Edelson, M. G. (2006). Are the majority of children with autism mentally retarded? A systematic evaluation of the data. *Focus on Autism and Other Developmental Disabilities*, 21, 66–83

Edelson, SM, Rimland, B, Berger, CL & Billings, D. (1998) 'Evaluation of a mechanical hand-support for facilitated communication' *Journal of Autism and Developmental Disorders*, Vol. 28, pp. 153–157.

Emerson, A, Griffiths, A, Prentice, A, Cosham, T, Howard-Jones, P, Grayson, A (1998) 'Evaluation of Facilitated Communication' *International Journal of Language & Communication Disorders*, Vol. 33, pp. 397-402

Emerson, A, Grayson, A & Griffiths, A (2001) 'Can't or won't? Evidence relating to authorship in facilitated communication', *International Journal of Language & Communication Disorders*, Vol. 36, pp.98–103.

Erickson, K. A., & Clendon, S. A. (2009). Addressing the literacy demands of the curriculum for beginning readers and writers. In C. Zangari & G. Soto (Eds). *Practically speaking: Language, literacy, and academic development for students with AAC needs* (pp. 195-215). Baltimore: Paul H. Brookes.

Filipek, P.A., Accardo, P.J., Baranek, G.T., Cook, E.H., Dawson, G., Gordon, B., Gravel, J.S., ... & Volkmar, F. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 29(6), 439-484.

Frith, U. (October 2012) Personal answer to question in AWARES online conference, *Autism 2012*, <http://www.awares.org/conferences/default.asp>.

Gernsbacher, M. A., Sauer, E., Geye, H., Schweigert, E., and Goldsmith H. H. (2008). Infant and toddler oral- and manual-motor skills predict later speech fluency in autism. *Journal of Child Psychology and Psychiatry*, 49, 43–50.

Gillam SL & Gillam RB (2006) Making evidence-based decisions about child language intervention in schools. *Lang Speech Hear Serv Sc.*, 37(4), 304-15.

Gillberg, C & Coleman, M (1992) *The Biology of the Autistic Syndromes*. 2nd edn, Mac Keith Press, London.

Gomstyn, Alice, (7 January 2012) *Not Just the Wendrows: Sex Abuse Cases Dismissed After Facilitated Communication*, ABC 2020, viewed 10 January 2012, <http://abcnews.go.com/Health/wendrows-sex-abuse-cases-dismissed-facilitated-communication/story?id=15274276>

- Gorman, BJ, (1999) Facilitated communication: rejected in science, accepted in court: A case study and analysis of the use of FC evidence under Frye and Daubert. *Behavioural Sciences and Law*, 17, 517-541.
- Grayson, A (1997) In Autism Research Unit (eds), *Living and Learning with Autism: The Individual, the Family and the Professional*, pp. 231-242. Autism Research Unit/National Autistic Society.
- Grayson A, Emerson A, Howard-Jones P & O'Neil L, (2011) Hidden communicative competence: Case study evidence using eye-tracking and video analysis. *Autism*. Epub ahead of print 28 April 2011.
- Green, G, (1992) *Facilitated communication: Scientific and ethical issues*. Papers presented at the E.K. Shriver Center University affiliated Program Service-Related Research Colloquium Series, Waltham, MA.
- Green, G. (1994). The quality of the evidence. In H. C. Shane (Ed.). *Facilitated communication: The clinical and social phenomenon* (pp. 157-226). San Diego, CA: Singular Publishing.
- Green, G (1996) Evaluating claims about treatment for autism. In Maurice, C, Green, G, and Luce, S (Eds) *Behavioural Interventions for Young Children with Autism* (pp. 15-28). Austin TX:Pro-Ed.
- Green, G & Shane, H (1994) 'Science, reason, and facilitated communication' *Journal of the Association for Persons with Severe Handicaps*, Vol 19(3), pp. 151-172.
- Greenhalgh T (2001) How to read a paper. (2nd edition) London: BMJ Publishing Group.
- Greenspan, SI (2001) 'The affect diathesis hypothesis: the role of emotions in the core deficit in autism and in the development of intelligence and social skills', *J. Dev. Learn. Disord.* Vol. 5, pp. 1-46.
- Greenspan, S Wieder, S Simons, R (1998) *The child with special needs: Encouraging intellectual and emotional growth*, Addison-Wesley/Addison Wesley Longman.
- Happe, F & Frith, U (2006) 'The weak coherence account: detail-focused cognitive style in autism spectrum disorders', *J. Autism Dev. Disord.* Vol. 36, pp. 5-25.
- Hardan, A., Kilpatrick, M., Keshavan, M., & Minshew, N. (2003). Motor performance and anatomic magnetic resonance imaging (MRI) of the basal ganglia in autism. *Journal of Child Neurology*, 18, 317-324.
- Hasson & Joffe (2007). *The case for Dynamic Assessment in speech and language therapy*. Open access, retrieved from <http://clt.sagepub.com/content/23/1/9.full.pdf+html>.
- Haynes, R.B., D.L. Sackett, J.M.A. Gray, D.F. Cook, and G.H. Guyatt (1996) Transferring Evidence from Research into Practice: The Role of Clinical Care Research Evidence in Clinical Decisions. *ACP Journal Club*, November/December, A14-A16.

- Haynes, R.B., P. Devereaux, and G.H. Guyatt (2002) Clinical Expertise in the Era of Evidence-Based Medicine and Patient Choice. *ACP Journal Club* 136:A11–A14.
- Heckler, S (1994) ‘Facilitated communication: A response by child protection’, *Child Abuse and Neglect*, Vol. 18, pp. 495–503.
- Hedley, D Young, R Gallegos, MAJ Salazar, CM (2010) ‘Bross-Cultural Evaluation of the Autism Detection in Early Childhood (ADEC) in Mexico’, *Autism*, Vol.14(2), pp93-112.
- Higginbotham, J., & Bedrosian, J. (1995). Subject selection in AAC research: Decision points. *Augmentative and Alternative Communication*, 11, 11–13.
- Hirshoren, A. & Gregory, J (1995) ‘Further negative findings of facilitated communication’, *Psychology in the Schools*, Vol.32, pp.109–113.
- Huble, AM & Zumbo, BD (1996) A dialectic on validity: Where we have been and where we are going. *Journal of General Psychology*, 123, 207-215.
- Hudson, A (1995) ‘Disability and Facilitated Communication – A Critique’. *Advances in Clinical Child Psychology*, Vol 17, pp.197-232.
- Iacono, T. (2004). Augmentative and alternative communication. In Reilly, S., Douglas, J. & Oates, J. (Eds). *Evidence based practice in speech pathology*. Whurr Publishers, United Kingdom.
- Iacono, T. & Caithness, T. (2009) Assessment issues. In P. Mirenda & T. Iacono (Eds.), *Autism spectrum disorders and AAC* (pp. 23-48). Baltimore: Paul H. Brookes.
- ISAAC, 2012, *Position Statement on Facilitated Communication*, <http://www.isaac-online.org/wp-content/uploads/Position-Statement-on-Facilitated-Communication.pdf>, accessed 17 May 2012.
- Jacobson, JW Mulick, JA & Schwartz, AA 1995, ‘A history of facilitated communication: Science, pseudoscience, and antiscience science working group on facilitated communication’, *American Psychologist*, Vol. 50, pp. 750 – 765.
- Janzen-Wilde, ML Duchan, JF & Higginbotham, DJ 1995, ‘Successful use of facilitated communication with an oral child’, *Journal of Speech and Hearing Research*, Vol. 38, pp. 658–676.
- Justice, L 2010, ‘When craft and science collide: Improving therapeutic practices through evidence-based innovations’, *International Journal of Speech-Language Pathology*, Vol. 12, pp. 79–86.
- Kana, R. K., Keller, T. A., Cherkassky, V. L., Minshew, N. J., & Just, M. A. (2006). Sentence comprehension in autism: thinking in pictures with decreased functional connectivity. *Brain*, 129(9), 2484-2493.

- Kangas, K., & Lloyd, L. (1988). Early cognitive skills prerequisites to augmentative and alternative communication use: What are we waiting for? *Augmentative and Alternative Communication*, 4, 211–221.
- Kanner, L. (1943). Autistic disturbances of affective contact. *The Nervous Child*, 2, 217–250.
- Kawamura M, Mochizuki S. Primary progressive apraxia. *Neuropathology* (1999); 19: 249±58.
- Kern, JK (2002) ‘The possible role of the cerebellum in autism/PDD: disruption of a multisensory feedback loop’, *Medical Hypotheses*, Vol. 59, pp. 255-260
- Kerrin, RG, Murdock, JY Sharpton, WR & Jones, N (1998) ‘Who’s doing the pointing? Investigating facilitated communication in a classroom setting with students with autism’, *Focus on Autism and Other Developmental Disabilities*, Vol. 13, pp. 73–79.
- Kezuka E. (2002) A history if the facilitated communication controversy. *Japanese Journal of Child Psychiatry*, 3. 317-327.
- Kingston, SDH (2012) *Freedom to Speak: Department of Disabilities reviewing alternative communication method for disabled*, Submitted for assessment, Queensland University of Technology, Journalism.
- Kline, RB (2008) *Becoming a Behavioral Science Researcher: A Guide to Producing Research That Matters*, Guilford Press, New York.
- Koziol, LF Budding, DE & Chidekel, D (2011) ‘From Movement to Thought: Executive Function, Embodied Cognition, and the Cerebellum’, *Cerebellum*, EPub ahead of print Nov. 9 2011.
- Kuhn, T (1996) *The Structure of Scientific Revolutions*, 3rd edn, University of Chicago Press, Chicago and London.
- Kvam, MH. (2000) Is sexual abuse of children with disabilities disclosed? A retrospective analysis of child disability and the likelihood of sexual abuse among those attending Norwegian hospitals. *Child Abuse & Neglect*, 24(8), pp. 1073–1084.
- Lancioni GA, O’Reilly MF, Cuvo AJ, Singh NN, Sigafoos J, and Didden D (2007) PECS and VOCAs to enable students with developmental disabilities to make requests: An overview of the literature. *Research in Developmental Disabilities*, 28, 468-488.
- Levant, RF (2005). *Report of the 2005 presidential task force on evidence-based practice*. American Psychological Association. <http://www.apa.org/practice/resources/evidence/evidence-based-report.pdf> Retrieved 10 February 2014.
- Levant, RF and Hasan, NT (2008) ‘Evidence Based Practice in Psychology’. *Professional Psychology, Research and Practice*, 39(6), 658-662.

Lewis-Beck MS, Bryman A, Futing Liao, T (2004) *The SAGE Encyclopaedia of Social Research Methods* at <http://srmo.sagepub.com.libraryproxy.griffith.edu.au/view/the-sage-encyclopedia-of-social-science-research-methods/n387.xml?rskey=fCwptG>.

Light, J. C. (1989). Towards a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, 5, 137-144.

Light, J C., & McNaughton, D. (2009). Addressing the literacy demands of the curriculum for conventional and more advanced readers and writers who require AAC. In C. Zangari & G. Soto (Eds). *Practically speaking: Language, literacy, and academic development for students with AAC needs* (pp. 217-245). Baltimore: Brookes.

Lof, G (2011) 'Science-based practice and the speech-language pathologist', *International Journal of Speech-Language Pathology*, Vol. 13(3): pp. 189–196

MacNeil, L. K., & Mostofsky, S. H. (2012). Specificity of dyspraxia in children with autism. *Neuropsychology*, 26(2), 165.

Magliaro, SG Lockee, BB Burton, JK (2005) 'Direct Instruction Revisited: A Key Model for Instructional Technology', *Educational Technology, Research and Development*, Vol.53(4), pp.41-55.

Maras, KL & Bowler, DM (2012) 'Eyewitness Testimony in Autism Spectrum Disorder: A Review'. *Journal of Autism and Developmental Disorders*, Epub ahead of print 10 March 2012.

Marge, D. K. (2003). A call to action: Ending crimes of violence against children and adults with disabilities. *Syracuse: SUNY Upstate Medical University*.

Mazerolle, P. and Legosz, M. (2012). *Facilitated Communication and Augmented and Alternative Communication: A review*. Accessed 8 August 2013 at <http://www.communities.qld.gov.au/resources/rtd/disclosure-log-dl-16-file01.pdf>

McCathren, R. B. (2000). Teacher-implemented prelinguistic communication intervention. *Focus on Autism and Other Developmental Disabilities*, 15(1), 21–29.

Messick, S. 1980. Test validity and the ethics of assessment. *American Psychologist*, 35, 1012-1027.

Miller, J., & Chapman, R. (1980). Analyzing language and communication in the child. In R. Schiefelbusch (Ed.), *Nonspeech language, and communication: Acquisition and intervention* (pp. 159–196). Baltimore: University Park Press.

Ming, X., Brimacombe, M., & Wagner, G. (2007). Prevalence of motor impairment in autism spectrum disorders. *Brain & Development*, 29, 565–570.

Minshew, N., Sung, K., Jones, B., & Furman, J. (2004). Underdevelopment of the postural control system in autism. *Neurology*, 63, 2056–2061.

- Minsheu, N., & Williams, D. (2007). The new neurobiology of autism. *Archives of Neurology*, 64, 945–950.
- Mirenda, P. (2008). A back door approach to autism and AAC. *Augmentative and Alternative Communication*, 24(3), 220-234.
- Mirenda P & Iacono T, 2009, *Autism Spectrum disorder and AAC*. Paul H Brookes Publishing Co, Baltimore, London Sydney.
- Montee, BB Miltenberger, RG & Wittrock, D (1995) ‘An experimental analysis of facilitated communication’, *Journal of Applied behavior Analysis*, Vol. 28, pp.189–200.
- Mostert, MP (2001) ‘Facilitated Communication Since 1995: A review of published studies’, *Journal of Autism and Developmental Disorders*, Vol. 31, pp. 287–313.
- Mostert, M. P. (2010). Facilitated communication and its legitimacy—twenty-first century developments. *Exceptionality*, 18(1), 31-41.
- Mostofsky SH & Ewen JB (2011) ‘Altered connectivity and action model formation in autism is autism’, *Neuroscientist*, Vol 17(4), pp. 437–448.
- Mundy P, Gwaltney M, Henderson H (2010) ‘Self-referenced processing, neurodevelopment and joint attention in autism’, *Autism*, Vol. 14(5), pp. 408-29.
- Mundy, P & Stella, J (2000) ‘Joint attention, social orienting, and nonverbal communication in autism’ in AM Wetherby & BM Prizant (eds.), *Autism Spectrum Disorders: A Transactional Developmental Perspective*, Paul H. Brookes, Baltimore, MD.
- Myles, B Simpson, RL & Smith, SM (1996a) ‘Collateral behavior and social effects of using facilitated communications with individuals with autism’, *Focus on Autism and Other Developmental Disabilities*, Vol. 11, pp. 163–169, 190.
- Myles, BS Simpson, RL & Smith, SM (1996b) ‘Impact of facilitated communication combined with direct instruction on academic performance of individuals with autism’ *Focus on Autism and Other Developmental Disabilities*, Vol. 11, pp. 37–44.
- National Health and Medical Research Council, 1999, *A guide to the development, implementation and evaluation of clinical practice guidelines*. Accessed 11 August at http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/cp30.pdf
- National Health and Medical Research Council, 2000a, *How to review the evidence: systematic identification and review of the scientific literature*. Accessed 11 August at http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/cp65.pdf
- National Health and Medical Research Council, 2000b, *How to use the evidence: assessment and application of scientific evidence*. accessed 11 August at http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/cp69.pdf
- National Joint Committee for the Communication Needs of Persons With Severe Disabilities. (2002). *Access to communication services and supports: Concerns*

regarding the application of restrictive “eligibility” policies [Technical Report]. Available from www.asha.org/policy or www.asha.org/njc. doi:10.1044/policy.TR2002-00233

National Joint Committee for the Communication Needs of Persons With Severe Disabilities. (2003). *Position statement on access to communication services and supports: Concerns regarding the application of restrictive “eligibility” policies [Position Statement]*. Available from www.asha.org/policy or www.asha.org/njc. doi:10.1044/policy.PS2003-00227

National Research Council. (2001). *Educating Children with Autism. Committee on Educational Interventions for Children with Autism*. C. Lord., & J.P. McGee. (Eds). Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

Niemi, J and Karna-Lin, E. (2002). Grammar and lexicon in Facilitated Communication: A linguistic authorship analysis of a Finnish case. *Mental Retardation*, 40, 347-357.

Notari, A. R., Cole, K. N., & Mills, P. W. (1992). Cognitive referencing: The (non) relationship between theory and application. *Topics in Early Childhood Special Education*, 11(4), 22–38.

Ogletree, BT Hamtil, A Solberg, L & Scoby-Schmelzle, S (1993) ‘Facilitated Communication: illustration of a naturalistic validation method’, *Focus on Autistic Behavior*, Vol. 8, pp. 1-13.

Olney, M (1995) ‘Reading between the lines: A case study on facilitated communication’, *Journal of the Association for People with Severe Handicaps*, Vol. 20, pp. 57–65.

Ornitz, E. M., Guthrie, D., & Farley, A. H. (1977). The early development of autistic children. *Journal of Autism and Childhood Schizophrenia*, 7(3), 207-229.

Oxford Centre for Evidence-Based Medicine (2001) *Levels of evidence and grades of recommendation*. Retrieved 3 January 2014, from www.cebm.net/index.aspx?o=1047.

Page, J. & Boucher, J. (1998). Motor impairments in children with autistic disorder. *Child Language Teaching and Therapy*, 14, 233–259.

Poplin, M.S. (1995) The dialectic nature of technology and holism: use of technology to liberate individuals with learning disabilities. *Learning Disability Quarterly*, 18(2), 131-140.

Poplin, M. Rogers, S.M. (2005) Recollections, Apologies and Possibilities. *Learning Disability Quarterly*, 28(2) 159-162.

Prizant, BM (2011) ‘The Use and Misuse of Evidence-Based Practice: Implications for Persons with ASD’, *Autism Spectrum Quarterly*, Fall 2011, pp. 43-49.

Prizant B & Wetherby A (1998) Understanding the continuum of discrete-trial traditional behavioral to social-pragmatic developmental approaches in communication

enhancement for young children with autism/PDD. *Seminars in Speech and Language*, 19, 329-352. doi:10.1055/s-2008-1064053

Prizant, B.M., Wetherby, A.M., Rubin, E., Laurent, A.C., Rydell, P.J. (2006) *The SCERTS Model – A Comprehensive Educational Approach for Children with Autism Spectrum Disorders. Volume 1. Assessment.* Paul H Brookes Publishing Company, Baltimore.

Prizant, B Wetherby, A & Rydell, P (1994) 'Implications of facilitated communication for education and communication enhancement in autism', in H Shane (ed.), *The clinical and social phenomenon of facilitated communication*, Singular Press, San Diego.

Prizant, B Wetherby, A & Rydell, P (2000) 'Communication intervention issues for children with autism spectrum disorders', in AM Wetherby & BM Prizant (eds.), *Autism Spectrum Disorders: A Transactional Developmental Perspective*, Paul H. Brookes, Baltimore, MD.

Probst, P. (2005). Communication unbound - or unfound? An integrative review on the effectiveness of facilitated communication (FC) in non-verbal persons with autism and mental retardation. *Zeitschrift fur Klinische Psychologie Psychiatrie und Psychotherapie*, 53, 2, 93-128.

Provost, B., Lopez, B., & Heimerl, S. (2007). A comparison of motor delays in young children: Autism spectrum disorder, developmental delay, and developmental concerns. *Journal of Autism and Developmental Disorders*, 37, 321–328.

Reichle, J., & Yoder, D. (1985). Communication board use in severely handicapped learners. *Language, Speech, and Hearing Services in Schools*, 16, 146–157.

Remington-Gurney, J, (1996) *Report on the use of Facilitated Communication by the Division of Intellectual Disability Services, 1992-6.* Department of Families, Youth and Community Care.

Remington-Gurney, J (2009) *A Slice of My Life: Facilitated Communication Training*, Options Communication Training Centre Pty. Ltd, Kallangur, Australia.

Remington-Gurney, J (2012) Queensland FCT Inc Home Page, <http://www.qldfctinc.com.au>, viewed 1 May 2012.

Rice, M., & Kemper, S. (1984). *Child language and cognition*. Baltimore: University Park Press.

Rogers, SJ & Bennetto, L (2000) 'Intersubjectivity in Autism: The Roles of Imitation and Executive Function', in AM Wetherby & BM Prizant (eds.), *Autism Spectrum Disorders: A Transactional Developmental Perspective*, Paul H. Brookes, Baltimore, MD.

Rogers, S., Bennetto, L., McEvoy, R. & Pennington, B. (1997). Imitation and pantomime in high-functioning adolescents with autism spectrum disorders. *Child Development*, 67, 2060–2073.

- Romski, M. A., & Sevcik, R. A. (1996). *Breaking the speech barrier: Language development through augmented means*. Baltimore: Brookes.
- Rothchild, I. (2006). Induction, deduction, and the scientific method. In *The society for the study of reproduction*. Accessed 22.12.2012 from http://www.ssr.org/Documents/2006-01-04Induction2.pdf?origin=publication_detail.
- Sackett, DL. Rosenberg, WMC. Gray, JAM. Haynes, RB. and Richardson, WS (1996) Evidence-Based Medicine: What It Is and What It Isn't. *British Medical Journal* 312:71–72.
- Satterfield, JM. Spring, B. Brownson, RC. Mullen, EJ. Newhouse, RP. Walker, BB. And Whitlock, EP. (2009) Towards a Transdisciplinary Model of Evidence-Based Practice. *The Milbank Quarterly*, 87(2), 368-390)
- Schlosser, R. W. (2004, June 22). Evidence-Based Practice in AAC. The ASHA Leader.
- Schlosser RW & Raghavendra, P. (2004). Evidence-based practice in augmentative and alternative communication, *Augmentative and Alternative Communication*, 20(1), 1-21.
- Schopler, E. (1992). Editorial commentary. *Journal of Autism and Developmental Disorders*, 22, 337-338.
- Secord, W. (1992, Fall). The use and abuse of standardized tests with children with special needs. *The Clinical Connection*, 19–23.
- Senechal C, Larivee S, Richard E & Robert Y, (2004). *Le vaccine RRO et autism: La disinformation a l'oeuvre*. *Revue de psychoeducation*, 33 (1), 205-227.
- Shane, H (ed.), (1994) *Facilitated communication: The clinical and social phenomenon*, Singular Publishing, San Diego, CA.
- Shane, H., & Bashir, A. (1980). Election criteria for the adoption of an augmentative communication system: Preliminary considerations. *Journal of Speech and Hearing Disorders*, 45, 408–414.
- Shadmehr, R & Krakauer, JW (2008) 'A computational neuroanatomy for motor control', *Exp. Brain Res.*, Vol. 185, pp. 359–81.
- Shadmehr, R & Mussa-Ivaldi, FA (1994), 'Adaptive representation of dynamics during learning of a motor task', *Journal of Neuroscience*, Vol. 14(5), pp. 3208-3224.
- Sheehan, CM & Matuozzi, RT (1996) 'Investigation of the validity of facilitated communication through disclosure of unknown information' *Mental Retardation*, Vol. 34, pp. 94–107.
- Sigafoos, J., Arthur, M., & O'Reilly, (2003). *Challenging behavior and developmental disability*. Baltimore: Brookes Publishing.

Sigafoos, J., & Schlosser, R. (2012). 'An experiential account of facilitated communication'. *Evidence-Based Communication Assessment and Intervention*, 6(1), 1-2.

Silverman, WK and Hinshaw, SP (2008) 'The second special issue on evidence-based Psychosocial treatments for children and adolescents: A 10-year update'. *Journal of Clinical Child and Adolescent Psychology*, 37(1), 1-7.

Simpson, RL & Myles, BS (1995) 'Facilitated communication and children with disabilities: An enigma in search of a perspective', *Focus on Exceptional Children*, Vol. 27, pp. 1–16.

Smith, M. (2003). *Literacy and Augmentative and Alternative Communication*. Elsevier, Academic Press Inc.

Smith, MD & Belcher, RG (1993) 'Brief report: Facilitated communication with adults with autism', *Journal of Autism & Developmental Disorders*, Vol. 23(1), pp. 175-183

Smith, LB & Thelen, E (2003) 'Development as a dynamic system', *Trends in Cognitive Sciences*, Vol. 7, pp. 343–348.

Speech Pathology Australia (2009) Position Paper: Evidence Based Speech Pathology Practice for Individuals with Autism Spectrum Disorder. http://www.speechpathologyaustralia.org.au/library/Clinical_Guidelines/ASD_EBP.pdf, accessed 4.9.13.

Speech Pathology Australia (2010) Position Paper: Evidence Based Practice in Speech Pathology. http://www.speechpathologyaustralia.org.au/library/position_statements/EBP_in_SP.pdf accessed 4.9.13.

Speech Pathology Australia (2012) *Augmentative and Alternative Communication Clinical Guideline*. Melbourne: Speech Pathology Australia.

Stone, W., Ousley, O., & Littleford, C. (1997). Motor imitation in young children with autism: What's the object? *Journal of Abnormal Child Psychology*, 25, 475–480.

Sullivan, PM & Knutson, JF. (2000) Maltreatment and disabilities: a population based epidemiological study. *Child Abuse & Neglect*, 24(10), 1257–1273.

Sutera, S., Pandey, J., Esser, E. L., Rosenthal, M. A., Wilson, L. B., Barton, M., Green, J. Hodgson, S. Robins, DL Dumont-Mathieu, T & Fein, D. (2007). Predictors of optimal outcome in toddlers diagnosed with autism spectrum disorders. *Journal of autism and developmental disorders*, 37(1), 98-107.

Tehan, G & Senior, G 2006, *Final report on Facilitated Communication project*, University of Southern Queensland.

The Australian Concise Oxford Dictionary, 1987, Oxford University Press, Melbourne.

Thelen, E 2004, 'The Central Role of Action in Typical and Atypical Development: A Dynamic Systems Perspective', in IJ Stockman (ed), *Movement and Action in Learning*

and Development: Clinical Implications for Pervasive Developmental Disorders, Elsevier Academic Press, San Diego, CA.

Thorndike, RM. 1997. *Measurement and evaluation in psychology and education* (6th ed.) Upper Saddle River , NJ: Pearson Education.

Tincani M and Devis K (2010) Quantitative synthesis and component analysis of single-participant studies on the picture exchange communication system, *Remedial and Special Education*, 32, 458-470.

Todd, J 2011, Wednesday Web Chat 15 June 2011,
<http://www.freep.com/article/20110612/NEWS03/110610060/What-facilitated-communication-Discuss-Wednesday-Web-chat>, viewed 15 June 2011.

Turkeltaub, PE; Flowers, DL; Verbalis, A; Miranda, M; Gareau, L; Eden, GF. (2004) The Neural Basis of Hyperlexic Reading. *Neuron* - 8 January 2004 (Vol. 41, Issue 1, pp. 11-25)

Tuzzi, A 2009, 'Grammar and lexicon in individuals with autism: A quantitative analysis of a large Italian corpus', *Intellectual and Developmental Disabilities*, Vol. 47(5), pp. 373-385.

UNCPRD (2006) United Nations Convention on the Rights of Persons with Disabilities. Retrieved from: <http://www.un.org/disabilities/default.asp?id=150>

Vaivre-Douret, L Lalanne, C Ingster-Moati, I Boddaert, N Cabrol, D Dufier, J Golse, B Falissard, B 2011, 'Subtypes of Developmental Coordination Disorder: Research on Their Nature and Etiology', *Developmental Neuropsychology*, Vol. 36(5)

Vazquez, CA, 1995, 'Failure to confirm the word-retrieval problem hypothesis in facilitated communication', *Journal of Autism and Developmental Disorders*, Vol. 25, pp. 597-610.

Vygotsky, L 1978, *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.

Wegner DM, Fuller VA, and Sparrow B, 2003. Clever hands: Uncontrolled intelligence in facilitated communication. *Journal of Personality & Social Psychology*, 85(1), 5-19.

Weimer, A. K., Schatz, A. M., Lincoln, A., Ballantyne, A. O., & Trauner, D. A. (2001). "Motor" impairment in Asperger syndrome: evidence for a deficit in proprioception. *Journal of Developmental & Behavioral Pediatrics*, 22(2), 92-101.

Weiss, MJ Wagner, SH & Bauman, ML 1996, 'A validated case study of facilitated communication', *Mental Retardation*, Vol. 34, pp. 220-230.

Wendt O, 2009. Research on the use of graphic symbols and manual signs. In P. Mirenda & T. Iacono (EDS.), *Autism Spectrum Disorder and AAC* (pp. 83-137). Baltimore: Paul H. Brookes.

Wetherby, A Prizant B & Schuler, A 2000, 'Understanding the nature of communication and language impairments' in AM Wetherby & BM Prizant (eds.), *Autism Spectrum Disorders: A Transactional Developmental Perspective*, Paul H. Brookes, Baltimore, MD.

Wetherby, A. M., & Prizant, B. M. (2003) *Communication and Symbolic Behavior Scales Developmental Profile (CSBSDP)*. Retrieved from www.brookespublishing.com/store/books/wetherby-csbsdps/checklist.htm.

Wilson, M 2012, Personal Correspondence.

Wing, L. (1981). Language, social, and cognitive impairments in autism and severe mental retardation. *Journal of Autism and Developmental Disorders*, 11(1), 31-44.

World Health Organisation (2001). International Classification of Functioning, Disability, and Health (ICF). World Health Organisation: Geneva. Retrieved from: <http://www.who.int/icidh/>.

Yoshida, H Nakamizo, S Kondo, M 2011, 'Perceptual characteristics of peripheral vision in children with autism.' *Shinrigaky Kenkyu*, Aug;82(3):265-9. Article in Japanese. Information obtained from abstract - <http://www.ncbi.nlm.nih.gov/pubmed/21919304>, accessed 20 January 2012.