

## **Response to the draft “ Proposed National Framework for Reducing the Use of Restrictive Practices in the Disability Service Sector (the ‘Proposed National Framework’) Consultation Version – May 2013”**

Many of the questions and comments in this response relate to more than one section of the draft. They are provided under the following headings.

- (1) Not enough information provided in the draft
- (2) Does the draft describe proper use of NDIS funding?
- (3) “Weasel words” or enforceable Human Rights Protections?
- (4) Workforce resistance to best practice is not acknowledged or addressed
- (5) There is no strategy to develop a qualified workforce.
- (6) Australia needs to train Board Certified Behaviour Analysts in Australian universities.
- (7) An appropriate benchmark for acceptable practices?

### **Not enough information provided in the draft.**

There is not enough detail in the draft to confidently conclude that the proposed strategies offer adequate human rights protection to people in restrictive interventions.

If this discussion paper is a genuine attempt to inform and consult with those who will carry most of the risks (i.e. people in restrictive intervention and their families), it is very disappointing that the risks, costs and benefits of the proposed strategy are not clearly stated.

To properly examine the proposed strategy a person would need to have sophisticated research skills, access to a university data base, an advanced understanding of the concepts/methods of evidence based practices, some direct experience of the difference in client outcomes in evidence based practice and non-evidence based practice, a detailed understanding of Australian legislation/case law and a great deal more information about the proposed strategies. It is beyond the capacity of carers and people in restrictive intervention to evaluate this discussion paper and reach an informed conclusion.

It is not clear who informed the draft paper and whether or not they have a track record of rehabilitating people out of restrictive intervention. Readers do not know if the draft is mainly informed by people who have never rehabilitated anyone out of restrictive interventions and have just read some journal articles. Readers do not know if the draft has been largely informed by union officials concerned about the workplace rights of their members. This makes it difficult for people in restrictive intervention and their carers to assess if the draft is properly informed and presents strategies which have realistic prospects of improving the welfare of people in restrictive intervention.

## **Does the draft describe proper use of NDIS funding?**

The draft does not clearly state the role of NDIS funding in any section. This leaves unanswered some fundamental questions about the role of insurance funding in this strategy and the human rights protections attached to that funding. Is the NDIS insurance funding meant to be insurance in the traditional sense – i.e. for the delivery of evidence based services to directly benefit people in restrictive intervention, following recognized protocols delivered by qualified persons, with the consumer having access to functional systems of redress when there is a departure from evidence based practice? Do consumers in restrictive intervention have the basic, enforceable right to terminate a restrictive intervention service that is not evidence based and not leading to a reduction in restrictive intervention? Can a consumer exercise the basic right to choose treatment from a properly qualified and regulated professional? Do they have the basic enforceable right to terminate the services of unqualified providers and opt for services from properly trained and supervised staff?

Is it proposed that the NDIS funding be directed to activity that should be funded from other sources? For example programs to improve staff performance to an acceptable level are properly funded from an operator's training budget, and not a client responsibility.

Similarly, programs that are experimental should be

- (1) funded from a separate research budget:
- (2) involve full disclosure to clients of risks/cost/expected benefits of the experiment compared to the evidence based approach, and
- (3) regulated in accordance with NHMRC legislation and terminated in a timely fashion if there is no benefit to the individual in restrictive intervention

People in restrictive intervention are extremely vulnerable and ought not be treated in the NDIS as an experimental resource or a staff training resource.

## **“Weasel words” or enforceable Human Rights Protections?**

It is troubling that the draft describes protection of human rights of people in restrictive intervention in terms that make these protections optional. For example (emphasis added).....

*“The NDIS legislation and rules recognise that there will be circumstances where the Agency **should** make a decision that a support must be provided by a qualified person or organisation that meets certain quality and practice standards”*

*“Clients of disability services **should** be active participants in decisions that affect their lives, support and care.”*

*“Commonwealth, State and Territory parties who will continue to be responsible for quality assurance systems in the interim **may** also explore the possibility of amending their regulatory frameworks to accompany this initiative. Further consideration will also be given to options regarding a national or nationally-consistent regulatory framework.”*

*“Safeguards **should**, over time, apply across Australia”*

It is my experience that Australian laws do not provide adequate human rights protection to people in restrictive intervention. In fact, I believe there is plenty of evidence that Australia’s current disability laws provide an unconditional state of grace for poor practice in restrictive intervention.

I make this comment in a number of capacities including as a litigant, as an advocate/friend at the Victorian Disability Commission, as an advocate/friend at many meetings with senior government managers responsible for restrictive interventions, as the author of a number of submissions to government, as a parent participant in the review of the 2006 Victorian Disability Act and as a visitor to a client in restrictive intervention.

As an aside – I have observed that the gorillas, elephants and orang-utans at the Melbourne Zoo have better care and protection of their rights than the client I saw in a Victorian restrictive intervention “home”. I was physically sickened by the visits to restrictive intervention, as was the parents and siblings of the person incarcerated there. This facility was regulated under the 2006 Victorian Disability Act which publicly promised to protect human rights of people in restrictive intervention.

### **Workforce resistance to best practice**

It is my experience in Victoria that parents, and guardians face systemic and vigorous resistance at all levels when they try to advocate for evidence based practice particularly with respect to restrictive intervention. My experiences as the parent of a child subjected to restrictive practices in Victoria made me very scared for the welfare of my whole family. In fact my family left Australia and moved to the USA purely so that our son could access evidence based intervention and education. Access to evidence based practice in the USA gave my son language and largely eliminated his behaviour of concern– a genuine positive behaviour support. In Australia, there was not evidence based practice of positive behaviour support. Indeed a very

high profile Australian expert representing two universities argued in court that my son had no capacity to learn. Service providers argued that the evidence based language interventions were too difficult for their untrained staff to understand and that there was no alternative to restrictive practice. I think my story is familiar to a great many families.

Workforce resistance to best practice is not acknowledged in the draft and is not addressed by the limited initiatives outlined in the draft.

### **There is no strategy to develop a qualified workforce.**

It is encouraging that the proposed strategy mentions positive behaviour support – which presumably is a reference to ABA methods. Most experts would regard ABA methods such as functional behaviour analysis and functional communication training as evidence based best practice for positive behaviour support. However Australia does not have a workforce trained to inform, lead, or deliver these interventions to people in restrictive intervention.

People in restrictive intervention do not have minor behavioural problems that can be resolved by a few simple procedures loosely based on ABA/PBS methods, led and implemented by persons with introductory level training and experience.

It is intensive, disciplined and skilled work to rehabilitate someone out of restrictive intervention. It is a job for formally qualified, experienced, “hands-on” ABA/PBS practitioners with sound clinical judgement – preferably on site daily, working directly with clients, coaching skilled staff, checking for implementation fidelity, evaluating effectiveness, revising and documenting procedures. Even highly trained clinicians working in this area need to make referrals to other clinicians when a client is not making progress.

By formally qualified, I do not mean a person with an Australian undergraduate degree in psychology, social work, disability studies or other social science discipline. Very few Australian registered psychologists are qualified by training or experience to develop, supervise, or implement an ABA/PBS program.

It is very unrealistic to expect quality ABA/PBS rehabilitation programs if programs are informed by unqualified professionals and led by unqualified managers.

### **Australia needs to train Board Certified Behaviour Analysts in Australian universities.**

In the USA, insurers and state licencing authorities generally require that ABA/PBS therapies are overseen by Board Certified Behavior Analysts (refer Behavior Analysts Certification Board

website, "Behavior Analysts Licencure/Certification Statutes"

<http://www.bacb.com/index.php?page=100170> . This is an important legal, ethical and human rights safeguard for insurers, funding agencies and the recipients of ABA/PBS services. Insurers and funding agencies recognize that ABA/PBS therapy run by unqualified practitioners, and not following recognized protocols can be very harmful to clients, a waste of money and an unacceptable business risk.

Just as important, poor quality ABA/PBS causes vulnerable families and guardians to erroneously conclude that ABA/PBS cannot work for their loved one in restrictive intervention.

No plan for developing an Australian BCBA workforce is outlined in the discussion paper. This is a significant flaw in the strategy. Based upon statements from Australia's senior experts I have read, heard in court and in other public forums, I think it is clear that Australian Universities do not understand many of the basic concepts and principles of ABA/PBS. This contributes to a systemic dissemination of poor practice leading to critical and avoidable errors in practice.

There are now more than 30 countries (including China and New Zealand) offering the Behavioural Analyst Certification Board training through their own universities. No Australian University offers this training. Australians wanting to obtain the BCBA certification must study at an overseas university, arrange and often pay for overseas BCBA's to supervise their practicum in order to meet certification board requirements. Making this training available from Australian universities would remove a significant barrier to best practice in Australian restrictive intervention.

### **An appropriate benchmark for acceptable practices?**

The draft implies that improvements will be measured against the current scenario of widespread human right abuse – which is unlawful. I don't think this type of benchmarking adequately protects human rights for people in restrictive interventions.

It would be better to consider the risk/cost/benefit comparison between the proposed strategies and the alternative best practice/evidence based strategy of implementing ABA/PBS with formally trained clinical staff (i.e. BCBA's and behavioural technicians) and with strict adherence to the recognized protocols and defining dimensions for ABA (i.e. applied, behavioural, analytic, technological, conceptually systematic, effective and generalized).