

Office of the Public Advocate (Queensland) Systems Advocacy

Response to Discussion Paper

Review of the Regulation
of Restrictive Practices in the
Disability Services Act 2006 and the
Guardianship and Administration Act 2000

August 2013

Public Advocate

The Public Advocate was established by the *Guardianship and Administration Act 2000* to undertake systems advocacy on behalf of adults with impaired decision-making capacity in Queensland. The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity (the adults) in all aspects of community life.

More specifically, the functions of the Public Advocate are:

- Promoting and protecting the rights of the adults with impaired capacity;
- Promoting the protection of the adults from neglect, exploitation or abuse;
- Encouraging the development of programs to help the adults reach their greatest practicable degree of autonomy;
- Promoting the provision of services and facilities for the adults; and
- Monitoring and reviewing the delivery of services and facilities to the adults.¹

Position of the Public Advocate

Intrinsic to this review is the need to ensure that upholding the human rights and the interests of people with intellectual disability or cognitive impairment is the primary focus when considering any potential changes to the regulatory regime in relation to restrictive practice use; a regime that was designed to facilitate improved outcomes and ensure appropriate safeguards and protections for people with disability subject to such practices.

The use of restrictive practices is a significant infringement on a person's human rights, in particular the right to liberty and security of the person and the right not to be subject to cruel, inhuman or degrading treatment or punishment. It is also potentially unlawful and may give rise to criminal or civil liability. It is therefore imperative that restrictive practices are only ever used as a last resort, that appropriate safeguards are applied and that there is appropriate monitoring and oversight of their use.

It has been five years since the introduction of the regulatory regime and the other systemic reforms aimed at reducing restrictive practice use in the disability services sector in Queensland. Given that the *Positive Futures* reforms were designed to provide an integrated legislative and practice response in which each of the respective elements complemented and supported the success of other elements, I am concerned that the focus of the consultation paper is so narrowly defined and is targeted primarily at the regulatory regime.

I am also concerned that there is little or no evidence presented in relation to the effectiveness to date of the regulatory regime and/or the complementary systemic reforms in reducing or eliminating the need to use restrictive practices. As a result, apart from anecdotal evidence and the results of the 2010 consultation outlined in the Discussion Paper, there is little on which I can base any objective assessment of the effectiveness of the regulatory regime, or whether there has been any undue compliance burden imposed on service providers that can be directly attributed to the regulatory component of the reforms.

I acknowledge and respect the views of service providers that have worked collaboratively with the Department since the introduction of the regime, and indeed I commend their efforts in seeking to implement a positive behaviour support approach and consequently improve the way in which they support their clients. However, without tangible evidence, it is difficult to determine whether it is the regulatory regime, the approach to implementation adopted by service providers, or the still-developing

¹ *Guardianship and Administration Act 2000*, s209

capability of staff to undertake and implement the necessary requirements of a positive behaviour support approach that is creating a 'burden' for service providers.

I am therefore of the opinion that in reviewing the effectiveness or otherwise of the regime, the Department should be mindful in terms of the relative weight accorded to the role of legislation versus that of the complementary structures and resourcing contributions established by both Government and service providers in implementing this reform.

Legislation is a blunt instrument for achieving the type of cultural change that is required to make a difference in the lives of vulnerable people with impaired decision-making capacity. In accordance with my belief that a true cultural shift will only be achieved when service providers understand and uphold in practice a rights-based approach to the way in which they support clients, I am concerned that the review will be self-limiting in its ability to influence the necessary requirements for sustainable outcomes for people with intellectual disability or cognitive impairment.

I am of the opinion that reviewing legislation in isolation of the supporting structures will limit the efficacy of the review by failing to address the factors that enable a cohesive and integrated system to evolve. In light of this, I am particularly interested in the effectiveness of the Specialist Response Service and the Centre of Excellence for Behaviour Support in building the capacity of the sector to reduce the reliance on the use of restrictive practices and improve the quality of life of people with intellectual disability and 'challenging' behaviour. I am also interested in how these resources will be invested in the future.

There must be increased transparency in relation to the investment in and effectiveness of the clinical, training and research resources allocated to the effort to reduce and eliminate the use of restrictive practices. I believe that there should also be a focus on developing educative and practical tools that will support staff to continue increasing their understanding and capability in incorporating positive behaviour support in their everyday practice, whether a client exhibits 'challenging' behaviours or not.

Overall my comments are provided in this context – emphasising the importance of a holistic approach to reducing and eliminating the use of restrictive practices incorporating both legislative and non-legislative strategies, as well as the immediate need to rectify the lack of transparency in relation to the use of restrictive practices in Queensland.

Response to the Discussion Paper

The regulation of restrictive practices – part of a broader context of system reform

As noted in my introductory remarks, Queensland's restrictive practices regulatory regime was introduced in 2008 as part of broader system reform aimed at reducing and eliminating the use of restrictive practices. Central to the *Positive Futures* reforms was a focus on positive behaviour support.

Prior to the introduction of the *Positive Futures* reforms, there were grave concerns expressed in the Report by the Honourable WJ Carter, *Challenging Behaviour and Disability: A Targeted Response* (the Carter Report)² about the disability sector's over-reliance on practices such as restraint and seclusion to manage people with intellectual disability as well as concerns "that these practices, which have no legislative support such as can be found in the Mental Health Act for the proper care of those with mental illness, are unlawful or at best are supported by legal paradigms which are of doubtful validity".³

The recommendation for a legislative framework to provide lawful authority and safeguards for the use of restrictive practices in the Carter Report was but one of many recommendations aimed at "a fundamental

² Hon W J Carter QC. *Challenging Behaviour and Disability: A Targeted Response* (Report to the Queensland Government 2006)

³ Hon W J Carter QC. *Challenging Behaviour and Disability: A Targeted Response* (Report to the Queensland Government 2006) 147

process of reform, renewal and regeneration of the DSQ and disability sector's response, which will provide an efficient, cost effective and financially sustainable outcome for the proper care and support of persons with intellectual disability and challenging behaviour across Queensland".⁴ The range of reforms recommended by Justice Carter and adopted by the Queensland Government included:

- An individualised and flexible approach which provides for and specifically addresses the person's specific needs and the circumstances of the individual case;
- A comprehensive multi-disciplinary assessment process in respect of the particular person with a view to the development of an individualised positive behaviour support plan for that person;
- An ongoing effective interaction between the assessment process and the intervention process within the community which will require coordination and individualised plan management at the regional level so as to ensure the effective maintenance and integrity of the total process in the best interests of the individual person;
- This process of assessment, intervention and coordination and individual plan management will operate collaboratively across the whole sector and will be available to and accessible by both DSQ and NGO service providers;
- The incorporation of the above into a Queensland Centre for Best Practice in Positive Behaviour Support under the leadership and management of a high profile and highly regarded practitioner supported by a suitably qualified Reference Group;
- The Centre for Best Practice will develop as a Centre of Excellence in ensuring the proper care and support of persons with intellectual disability and challenging behaviour. It will also develop as a valuable research facility and itself become a valued research resource. Its role will include community development and education;
- The immediate establishment of suitable accommodation to enable an immediate and effective response in those cases which require emergency management;
- The urgent and planned development of a range of accommodation options which respond to the need for secure care, transitional accommodation arrangements and community living for the target group;
- The recruitment and development of suitably qualified allied health and other support staff specifically for persons with intellectual disability and challenging behaviour and ensuring their ongoing training and professional development;
- The incorporation of the Centre into and as a distinct specialist segment within DSQ.⁵

I am particularly keen to ensure that this focus on the broader practice and system initiatives aimed at building the capacity of the sector to implement positive behaviour support approaches to reduce and eliminate the need for restrictive practices is not lost.

At the time of the Government response to the Carter Report, it was announced that \$113 million would be invested to implement the initiatives, with the Specialist Response Service and the Centre of Excellence for Behaviour Support as two key initiatives in this regard.⁶ I believe that there needs to be an ongoing commitment to and investment in building the capacity of the system and the sector for reasons that I will outline below.

It has now been five years since the commencement of the legislation and the implementation of these reforms. If these initiatives have been successful we would expect to see a reduction in the use of restrictive practices and an increase in the sector's capacity to implement positive behaviour support strategies. Again while anecdotal evidence suggests that improvements are taking place, I am unable to objectively measure whether there has been a reduction in the use of restrictive practices due to the lack of publicly available data.

⁴ Hon W J Carter QC. *Challenging Behaviour and Disability: A Targeted Response* (Report to the Queensland Government 2006) 9

⁵ Hon W J Carter QC. *Challenging Behaviour and Disability: A Targeted Response* (Report to the Queensland Government 2006) 10

⁶ Disability Services Queensland *Investing in Positive Futures: Response to Recommendations*, (2007) 3

In relation to the whether there has been an increase in the sector's capacity and capability to implement positive behaviour support strategies and embed this in a way that provides for an overall practice and culture shift, I also have little evidence to rely upon, with the exception of that discussed in the next section.

Capability and capacity of the sector – positive behaviour support

The Carter Report was adamant in its assertion that any legislative framework for the use of restrictive practices should prohibit the use of restrictive practices unless they are independently approved as part of an individualised positive behaviour support plan consequential upon a comprehensive assessment of the individual and his/her needs. The aim of the positive behaviour support plan being to outline strategies to meet the adult's needs, improve the adult's capabilities and quality of life and reduce or eliminate 'challenging' behaviours and the need for restrictive practices.

Anecdotally I am aware that the *Positive Futures* reforms have brought about positive changes in the way care and support is provided to adults with intellectual disability or cognitive impairment who exhibit 'challenging' behaviours and that there is now a greater understanding of positive behaviour support. However, as previously noted, I have little evidence to rely upon to objectively assess the sector's capacity in this regard.

The exception is the recent clinical audit and practice review of positive behaviour support plans conducted by Dr Liz Kiata-Holland, Fiona Davis, Simon Wardale and Professor Karen Nankervis at the Centre of Excellence for Behaviour Support, which indicates that positive behaviour support plans in Queensland are overly focused on compliance with the legislative framework and not meeting basic standards when it comes to those aspects of the plan focus on applied behaviour analysis.⁷ Having said that, the limitations inherent in the plans reviewed would suggest that despite many of them being 'approved', they may still not be fully legislatively compliant.

More specifically, the plans do not adequately identify why the 'challenging' behaviours are occurring or identify replacement behaviours that can be taught and strategies for teaching them, core strategies of the positive behaviour support approach. The research indicated that of the 139 plans audited against the Behaviour Support Plan Quality Evaluation scoring guide version II (BSPQEII), the mean score was 6.53. Given that a score of 12 or under indicates that a plan is not of acceptable quality and should be rewritten, the results indicate a very poor quality of plans for this study.

These results are very concerning given that Queensland has had five years of implementing these reforms and a very significant investment in building the capacity of the sector to implement positive behaviour support. Legislation alone will not change practice nor build capability. It is important that there is:

- An ongoing and targeted investment in developing the sector's capacity to implement a positive behaviour support approach;
- Effective clinical leadership and oversight for assessment, planning, implementation and review;
- Appropriate data collection and research to determine the effectiveness of these initiatives;
- Monitoring of the use of restrictive practices in Queensland; and
- Support for people subject to restrictive practices to make choices and exercise their rights.

Investment in developing the sector's capacity in implementing positive behaviour support

While the legislation is quite structured in its requirements, it is reasonable to assume that this has, in part, contributed to enhancing the understanding of what constitutes a positive behaviour support approach. Again, without objective data with which to analyse this, it is difficult to draw any strong conclusions to this

⁷ Kiata-Holland, Liz. Davis, Fiona. Wardale, Simon. Nankervis, Karen (2013) A Clinical Audit and Practice Review of Positive Behaviour Support Plans in Queensland, Unpublished Research, Centre of Excellence for Behaviour Support

effect. As a starting point, the requirements of the legislation have ensured that the minimum components of a positive behaviour support approach are attended to by service providers, and have also provided for appropriate safeguards in respect of decision-making and oversight.

Having said that, further investment in developing the sector's capacity would appear to be warranted in the interests of ensuring that service providers continue to pursue a rights-based approach to how they assess the least restrictive way by which to keep people safe from harm while providing appropriate opportunities for inclusion and participation in community life.

Given that the implementation of these reforms is now five years in, the focus should now be on how best to bridge any gaps that may still exist with respect to the sector's understanding of the legislative requirements while capitalising on the gains that have been made in terms of cultural and practice shifts.

I am concerned that making changes to the regulatory regime at this stage may only serve to confuse the sector about what is required of them and could potentially undermine the successes that have already been achieved with respect to reducing the use of restrictive practices.

There should be an ongoing multi-faceted approach to building the understanding and capability of direct support staff, management and the sector more broadly. This should include an ongoing focus on the development of educative resources as well as practical tools that will enhance practice.

I would recommend that an analysis of the sector's needs with respect to education and training is undertaken as a priority. The information obtained from such a review should be used to inform the development of practice guidelines and/or training opportunities that will further enhance and develop both the capacity and capability of the sector.

There is significant potential to work collaboratively across government and non-government service providers to share learnings and generate evidence-based resources that focus on ensuring end-to-end understanding of what constitutes best practice in positive behaviour support. This should encompass the full range of elements spanning from ensuring that staff clearly understand the communicative nature of 'challenging' behaviour through to how best to generate appropriate 'replacement' behaviours through to understanding the importance of data collection, analysis and review, and how to do this well.

This investment is just as important, if not more so, than any potential changes to the regulatory regime.

Clinical leadership and oversight

The importance of clinical oversight by experienced and qualified clinicians, particularly with respect to the preparation and implementation of positive behaviour support plans, is crucial to the regime. It is not the primary responsibility of decision-makers, such as guardians for restrictive practice matters or the Queensland Civil and Administrative Tribunal (QCAT) to assess the clinical efficacy of a positive behaviour support plan or its implementation, nor do they have expertise in this regard. Rather decision-makers must be provided with advice and evidence regarding the efficacy of these plans.

The significant investment in clinical resources made by the Department as part of the *Positive Futures* reforms should be made available to both build the capacity of the sector and provide expert advice to decision-makers about the efficacy of the positive behaviour support plans that are presented with an application for approval/consent to use restrictive practices. Other types of support for decision-makers may include guidelines for example about what an effective plan should include.

Furthermore, these clinical resources should be applied in such a way as to build capability at all levels of service provision by working 'with' and not 'for' service providers and, in doing so, to provide further education and training at the coal-face.

Use of data to inform practice and monitor the effectiveness of strategies to reduce the use of restrictive practices

The lack of available data on the use of restrictive practices in Queensland is unacceptable. Given that there is no data to show the effectiveness or otherwise of these strategies to reduce the use of restrictive practices, it is therefore not possible after five years of investment in legislative, educative, clinical and other resources to say with any certainty which, if any, of these initiatives have worked.

Monitoring the use of restrictive practices is the only way to measure whether strategies for reducing and eliminating the use of restrictive practices are working, and arguably the only way to really reduce and eliminate restrictive practices.

For these reasons, monitoring and data collection must start as soon as possible. This monitoring should be multi-faceted and focus not just on legislative compliance but also on improvements in service provider understanding and capability.

As a statutory advocate responsible for systemic advocacy on behalf of adults with impaired decision-making capacity, access to any data that is collected in relation to the use of restrictive practices would be of significant benefit to performing the functions of my role. I would respectfully suggest that any legislative requirement to report on the use of restrictive practices also requires that this data is made available to the Public Advocate. In the interests of openness and transparency, I would also recommend that publically available reports be produced, for example through the Annual Reporting process.

Monitoring

The current arrangements for monitoring the use of restrictive practices are inadequate. While data collection is important, there must be an entity that is responsible for collecting that data, and positive powers to monitor the use of restrictive practices by disability service providers. While the *Disability Services Act 2006* contains compliance provisions, these are focused on managing the contractual relationship between the Department and the funded non-government organisations. Auditing is focussed on compliance with a very generic set of Human Services Quality Standards.

There should also be a direct link between the Community Visitors who visit and inspect residential disability services where restrictive practices are used and the monitoring entity so that issues in relation to the use of restrictive practices can be reported with a view to providing further education and skill development where it is identified as being required.

Support for people subject to restrictive practices to make choices and exercise rights

In addition to regular reviews, there is a right for a person subject to restrictive practices to seek a review of containment and seclusion or the appointment of a guardian for restrictive practice matters at any time. While this is an important right, to be an effective right, people with disability need support to exercise it.

People with disability who are subject to restrictive interventions are often highly vulnerable, have limited communication abilities and there is a significant potential for their human rights to be violated and for abuse to occur.

Strategies, resources and tools must be developed to assist people with intellectual disability or cognitive impairment to exercise choice and control, make decisions about whether they are getting good outcomes from the services and supports they purchase, and protect themselves from abuse, neglect and exploitation.

This approach should be part of a range of strategies aimed at the prevention of abuse, neglect and exploitation of people with disability.

Unfortunately in the five years since the implementation of the reforms associated with the Carter Report, there have been few initiatives aimed at supporting people with intellectual disability or cognitive impairment subject to restrictive practices to exercise their rights under this regime.

Other legislation issues

Which restrictive practices should be regulated?

Given there is sometimes a lack of clarity in relation to whether a specific action constitutes a restrictive practice for the purposes of the legislation, it may be helpful to introduce an overarching definition that gives emphasis to the assertion that an action is a 'restrictive practice' if it is used for the purpose of controlling an adult's behaviour that may cause harm to the adult or others. This would eliminate actions such as those to assist activities of daily living, but capture those that are used in response to 'challenging' behaviours.

There are some restrictive practices however that should never be sanctioned, and thus should not form part of any regulatory framework. Consequence-driven strategies or psychosocial restraints that may include, for example, withdrawing personal items or activities or telling a person to stay in a particular physical position or part of a room or house until the person 'behaves correctly' must not be included.

The problem with these strategies is that they tend to be punitive in nature, highly susceptible to misuse or abuse, and there is little evidence to suggest that they have any long-term efficacy or impact in their use. The use of such strategies is also highly problematic for people with impaired decision-making capacity who may not have the cognitive ability to understand the reason for the 'punishment' and thus understand what is required in terms of modifying their behaviour.

I would like to believe that consequence-driven strategies would never be approved as a restrictive practice (restricting access to objects) under the current regime. However, the regulation of restricting access to objects has enabled a light to be shone on those practices that may for example be punitive in nature, such as removing personal items as a punishment for 'bad' behaviour, which perhaps previously were practiced without scrutiny.

For that reason I retain some concerns about a blanket approach to removing the requirement to seek approval for restricting access to objects. There is, however, a clear need to address the confusion that currently exists between a service provider exercising appropriate duty of care with respect to items that would usually be safely stored in the average domestic home.

Decision-making

Queensland has by far one of the most complex decision-making regimes for restrictive practices, with the provision for five different decision-makers. A contributing factor to this is the separate decision-making regime for the use of restrictive practices in community access and respite services.

It is important that the decision-maker who approves the use of restrictive practices must be independent from the service provider who seeks to use restrictive practices. From my perspective, the decision-maker should neither provide services nor provide funding for service provision; this should eliminate the Department of Communities, Child Safety and Disability Services as a potential decision-maker.

The decision-making regime could potentially be simplified by reviewing the requirements for community access and respite services with a view to aligning the decision-making process with that required by accommodation and community support providers. Any such review should ensure that any proposed changes are unlikely to necessitate additional resourcing, which could negatively impact on access to respite and community access services for people exhibiting 'challenging' behaviours.

Transitioning to a new service provider

A crucial component of a functional assessment carried out to inform the development of a positive behaviour support plan is the person's environment, including their physical environment, staff and the manner in which support is provided. Therefore when a person moves to a new service provider, their environment changes; this includes their routines and the way staff or others interact with the adult.

An environmental change can also be extremely significant for an adult and can therefore impact on their behaviour. New service providers also need to be provided with the guidance and support to understand and implement the strategies identified in the positive behaviour support plan; strategies that guide service provision, promote the acquisition of functionally-equivalent replacement behaviours, and reduce or eliminate the use of restrictive practices.

For these reasons I think that, at minimum, any positive behaviour support plan in place for an adult should be reviewed when they transition to a new service provider. There should also be clear timeframes within which this should take place as well as timeframes within which a new or updated assessment must be undertaken and the positive behaviour support plan updated accordingly. These processes should include provisions for new staff to be provided with clinical guidance and support when an adult is moved to a new service provider.

The legislation should provide for the flexibility for this to occur without the automatic necessity for a new containment and seclusion approval or new appointment of a restrictive practice guardian, so long as certain safeguards (such as timeframes within which review/reassessment should occur) are in place and new restrictive practices are not sought to be used by the new service provider.

Where there is an approval for containment or seclusion, QCAT should be provided with the details of the new provider and details regarding timeframes within which the plan will be reviewed, and the need for ongoing use of restrictive practices reassessed. QCAT would then have the discretion to review the containment and seclusion approval if deemed necessary.

Where a guardian for restrictive practice matters is appointed, both QCAT and the guardian should be provided with the details of the new provider, and details regarding timeframes within which the plan will be reviewed, and the need for ongoing use of restrictive practices reassessed. The guardian may choose to consider their ongoing consent to the use of restrictive practices and QCAT would also have the discretion to review the appointment of the guardian for restrictive practice matters.

Where the new service provider seeks to use new types of restrictive practices, then barriers to the application for a short-term approval should be removed. In the case where a guardian for restrictive practice matters is appointed (and there is no containment and seclusion approval), these barriers to gaining a short term approval were removed in 2010.⁸ In the case where there is a containment and seclusion approval by QCAT, consideration could be given to allowing a short-term approval to be provided, with a notice to QCAT. QCAT could then have the opportunity to either approve the other practices (with an updated assessment and plan) or to request that another application be made.

It is important that there is flexibility to allow the key players in the system to exercise discretion, but that safeguards are maintained. This balance can be achieved.

Timing of reviews

The primary purpose of a review is to assess how well the positive behaviour support plan is being implemented, whether there have been improvements in the adult's circumstances and to determine whether there is an ongoing need for the use of restrictive practices. At the time of the review it would be important for the decision-maker to see evidence of how the positive behaviour support plan has been implemented and the progress that has been made towards reducing and eliminating the use of restrictive

⁸ *Justice and Other Legislation Amendment Act 2010*

practices. Reviews should be separated from the issue of the maximum length for the approval of restrictive practices. It is important that restrictive practices cannot be used indefinitely and a maximum length for approval is a crucial safeguard in that respect.

Currently, where containment and seclusion is approved, an approval can only be given for a maximum of 12 months. Also during that time, the practice must be reviewed at least once. Given the significant incursion on a person's liberty and rights by the use of containment and/or seclusion I would not support extending the maximum time for approval of containment and/or seclusion to greater than 12 months.

A guardian for restrictive practice matters can be appointed for up to 12 months and there must also be a review at least once during the term of the guardian's appointment. Presumably the guardian who consents to the restrictive practice may impose a maximum length of time for which a restrictive practice may be used as part of the conditions of that consent before another consent is required.

I would be supportive of providing QCAT with the discretion to appoint a guardian for restrictive practice matters up to a maximum of two years, provided there were regular reviews during that time. If positive behaviour support plans are developed to a good standard, it should be relatively simple for service providers to show progress, or otherwise, in relation to their implementation, evidence of which should be available at these reviews.

Determining capacity

To appoint a guardian for restrictive practice matters or approve the use of containment and seclusion, QCAT must be satisfied that an adult has impaired capacity for making decisions about the use of restrictive practices.⁹ Each time a new approval for containment and seclusion is provided (after 12 months) or a guardian for restrictive practice matters is re-appointed (currently after 12 months), the adult's capacity for restrictive practice matters must again be assessed.

Given the presumption at common law, reflected in the *Guardianship and Administration Act 2000*, of capacity for all adults, this determination of capacity is important. I am aware that other states that regulate restrictive practices do not require a consideration or determination of capacity for these matters. However I have a number of observations to make about this process.

First, the assessment of capacity occurs quite late in the process for adults subject to restrictive practices. Usually a short-term approval may have been made and an assessment undertaken and the plan developed, prior to the application to QCAT (for containment and seclusion or the appointment of a guardian for restrictive practice matters). I am keen to ensure that proper consideration is given to the issue of capacity.

Second, I trust that ongoing assessment of the adult's capacity occurs. An indicator of the success of a positive behaviour support plan may, for example, be the development of the adult's capacity to understand restrictive practices.

Positive behaviour support plans

For me whether a positive behaviour support plan would be an effective plan should be the most important consideration, rather than simple compliance with the current list of factors in section 123L *Disability Services Act 2006*. In making a determination of effectiveness, consideration would need to be given to ensuring that the plan identifies the reasons for and antecedents to 'challenging' behaviour and the strategies to reduce 'challenging' behaviours, including the strategies that will be pursued to encourage the adult to develop functionally equivalent replacement behaviours. Ultimately the effectiveness of a plan, however, will be measured by its ability to, over time, reduce or eliminate the incidence of 'challenging' behaviours and thus the need to use restrictive practice. This should always be the primary focus of any review of the plan and its implementation.

⁹ Guardianship and Administration Act 2000, s80V(2)(a); s80ZD(1)(a)

There are other factors that decision-makers must be satisfied of prior to providing consent to the use of restrictive practices; these are set out in sections 80V and 80ZE of the *Guardianship and Administration Act 2000*. The information required to validate the provision of consent must be provided to decision-makers but need not be in the actual positive behaviour support plan.

As discussed earlier, if there is appropriate clinical guidance and oversight provided in relation to the preparation of plans, and decision-makers are provided with clinical advice about the efficacy of plans, this should reduce the current compliance-driven approach to positive behaviour support plans as followed by both those who prepare the plans and decision-makers who provide *de facto* approval of the plans via the consent process. More importantly, this should lead to the development of plans that are both effective in reducing the use of restrictive practices and in improving the adult's quality of life.

Use of anti-libidinal medication

Anti-libidinal medications are commonly used in the management of sex offenders. The most common anti-libidinal medications used are Androcur (cyproterone acetate) and Depoprovera (medroxyprogesterone acetate). They are sometimes collectively described as anti-androgen medication as they act to reduce the levels of male hormones such as testosterone with the aim of reducing sex drive. I have a number of concerns about the administration of these medications to people with impaired decision-making capacity in Queensland, including as chemical restraint under the *Disability Services Act 2006* and the *Guardianship and Administration Act 2000*.

Efficacy

This medication has limited evidence for its efficacy in treatment of problematic sexual behaviours in sex offenders generally, but particularly for people with intellectual disability.¹⁰ Some research emphasises that while anti-androgens may be effective in reducing physiological arousal, they do not necessarily act on sexual interest or direction. Further, physiological arousal can be peripheral to the motivations of problematic sexual behaviour in sex offenders.

Side-effects

Side-effects, including severe side-effects are associated with the use of both Androcur and Depoprovera. With Androcur, the most common anti-libidinal used, side-effects include breast development, weight gain, thrombotic pneumonia, liver toxicity, depression, gallstones, diabetes mellitus and osteoporosis, including increased propensity to broken and fractured bones after long-term use. Depoprovera, on the other hand, is associated with weight gain, headaches, nausea, lethargy and loss of bone density.

Given the severe side-effects of Androcur in particular, research indicates that the use of Androcur must be carefully managed medically, and monitored for the effects of feminisation, depression, emotional disturbances (every 1–3 months), liver functioning (every month) blood cell count, calcium and phosphate blood levels, blood pressure, and weight (every six months). Bone mineral density must be checked every year in case of increased osteoporosis risk.¹¹ I am not aware of the extent to which this monitoring occurs in relation to people with intellectual disability or cognitive impairment who are administered Androcur as a restrictive practice.

¹⁰ Susan Hayes et al Anti libidinal medication and people with disabilities – long term follow up of outcomes following third part consent to medication for problematic sexual behaviour: report to the criminological research council (2002) 12

¹¹ F Thibaut et al 'The World Federation of Societies of Biological Psychiatry: Guidelines for the biological treatment of paraphilias', (2010) *World Journal of Biological Psychiatry*, 11, 604-5

Ethical considerations

The use of anti-libidinal medication with sexual offenders, particularly where it is coerced or administered as a condition of release from prison, has been widely criticised from an ethical standpoint. Apart from the serious side-effects and lack of proven efficacy, the medication has been described as effecting a reversible ‘chemical castration’,¹² and this decision about whether to take away a person’s ability for physiological arousal is associated with many ethical and rights dilemmas.

Consent

One of the key issues for the use of anti-libidinal medication with people with impaired decision-making capacity is who can and should give consent for the administration of this medication. Of most concern, expressed by the Mental Health Court, QCAT and the Queensland Law Reform Commission is whether this medication can be administered lawfully to people with impaired decision-making capacity in Queensland. In summary, all parties have thrown serious doubt on whether anti-libidinal medication can be administered as health care in accordance with the *Guardianship and Administration Act 2000*.

In the case of *re AAG*,¹³ the tribunal found that on the evidence before it, the primary purpose for the use of Androcur was the control of AAG’s behaviour and was not being used for the proper treatment of a diagnosed mental illness or physical condition. Ultimately the tribunal did not make a determination about the scope of personal matters or health care. The matter was adjourned, and at a subsequent hearing the tribunal appointed the Adult Guardian as AAG’s guardian for restrictive practices on the basis that the administration of Androcur was a chemical restraint.

Queensland Law Reform Commission

In its report, *A Review of Queensland’s Guardianship Laws*,¹⁴ the Queensland Law Reform Commission (QLRC) focused specifically on the issue of administration of anti-libidinal medication as part of the chapter on restrictive practices. The QLRC drew attention to the ambiguity in relation to consent to the use of anti-libidinal medication for people with impaired decision-making capacity and specifically whether the use of anti-libidinal medication for the purpose of behavioural control could be consented to by a guardian or whether it constituted chemical restraint under the *Disability Services Act 2006*.

The QLRC recommended that reviews of the *Disability Services Act 2006* consider:

- Whether, and if so how, the restrictive practices legislation should regulate the use of anti-libidinal drugs, including in particular whether:
 - it is appropriate for anti-libidinal drugs to constitute ‘chemical restraint’ under the restrictive practices legislation or whether their use should require tribunal approval; and
 - there should be any specific requirements for a positive behaviour support plan that is developed for an adult to whom an anti-libidinal drug is administered; or
- Whether anti-libidinal medication, when administered as a form of behavioural control, should constitute a category of ‘special health care’ under the *Guardianship and Administration Act 2000* (Qld) and the *Powers of Attorney Act 1998* (Qld).¹⁵

In New South Wales, anti-libidinal medication (or treatment that involves the use of androgen-reducing medication for the purpose of behavioural control) is classified as “special medical treatment”, and as such only the guardianship tribunal can provide consent for its use in relation to people with impaired decision-making capacity.¹⁶

¹² Re AAG [2009] QGAAT 43

¹³ Re AAG [2009] QGAAT 43

¹⁴ Queensland Law Reform Commission, *A Review of Queensland’s Guardianship Laws* (Report no 67, 2010)

¹⁵ Queensland Law Reform Commission, *A Review of Queensland’s Guardianship Laws* (Report no 67, 2010) 385

¹⁶ *Guardianship Act 1987* (NSW) s33(1); *Guardianship Regulation 2005* (NSW) cl 9(b)

I strongly advocate for the exclusion of anti-libidinal medication from the restrictive practices regulatory regime. Given the complex legal, ethical, clinical and medical efficacy issues associated with its use, anti-libidinal medication should only be administered to people with impaired decision-making capacity as a type of special health care under the *Guardianship and Administration Act 2000*, and thus only able to be consented to by QCAT on the basis of expert clinical advice.

National Disability Insurance Scheme

In June of this year I provided a submission to the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) on the Proposed National Framework for Reducing the Use of Restrictive Practices in the Disability Service Sector (the 'Proposed National Framework').

Australia is in the early stages of forming policy and program responses and pursuing the regulation of restrictive practices. Given this, and the fact that states and territories currently have responsibility for the provision of disability services, there exists a disparate approach to the policy, program and legislative response to restrictive practice use across Australia.

I appreciate therefore that heading towards a nationally consistent approach will have challenges, and that using existing state/territory legislation and contractual arrangements in the interim is a sound approach. Having said that, I detailed a number of concerns with this strategy in my submission to FaHCSIA, which I would also like to also express to the Queensland Government.

Commitment to not reducing current safeguards

The current Queensland regulatory framework contained in the *Disability Services Act 2006* (DSA) and the *Guardianship and Administration Act 2000* (GAA) contains a relatively high level of safeguards when compared to some other states and territories. For example, consent to use restrictive practices is provided by an entity or person independent from the service provider seeking to use the practices. Importantly, restrictive practices can only be approved if a functional assessment has been undertaken for the person, and where this assessment informs the development of a positive behaviour support plan, which is regularly reviewed.

I advocate strongly for a national approach to regulation that does not result in any diminishing of the safeguards currently in place in Queensland for people with disability. This must be an underlying premise for any national approach. The Queensland Government has an important responsibility in this regard. Queensland must not be part of a national approach to disability services that results in a diminishing of safeguards or rights for people with disability who exhibit 'challenging' behaviours.

Concerns associated with individual contractual arrangements

As we progress towards a NDIS, many states and territories, including Queensland, are focusing on the importance of a person-centred approach to the provision of disability services, including the provision of individualised or self-directed funding.

Queensland launched the *Your Life Your Choice Self Directed Support Framework* in September 2012. It is a phased approach to self-directed funding. The first stage implements a host provider model under which people with disability are provided with individual allocations of funding that are auspiced through host providers. These host providers work with the person to plan and purchase their support services.

The next phase, enabled by amendments to the *Disability Services Act 2006* to allow funding to be provided directly to individuals, will allow individuals to directly receive the funding into their own bank accounts and purchase their own services directly. These changes to the way funding is provided and services purchased will not only provide more choice and control for people with disability, and assist Queensland to move towards a NDIS, but will potentially lead to significant changes in the way disability services are funded and delivered.

Increasingly 'block funding' of services will become a thing of the past. New services will enter the market and people will be purchasing their supports from a range of service providers, not just 'disability services' funded by the Department of Communities, Child Safety and Disability Services ('the Department') or Government more generally.

While these reforms are welcome and integral for a person-centred approach to the provision of disability support, they do pose new challenges for maintaining quality standards and safeguards, particularly in relation to the use of restrictive practices.

In Queensland only 'funded disability services' are regulated by the restrictive practices regulatory regime. Therefore where a person with a disability directly purchases services from a provider that is not funded by the Department, the regulatory regime will not apply. This means that not only will the safeguards of this regime not apply to individuals accessing such services, but these services will also not receive the immunity from civil and criminal liability that is provided under the *Disability Services Act 2006* if they use restrictive practices honestly and without negligence in accordance with the legislation.¹⁷

I am concerned about the increasing potential for the unregulated use of restrictive practices under direct funding models both in the current roll-out of self-directed funding in Queensland and under a NDIS. Planning needs to start now in relation to how there will be continuing safeguards, including regulation of the use of restrictive interventions for people with impaired decision-making capacity, particularly those with intellectual disability or cognitive impairment in Queensland, through Disability Care.

This being said, however, people with intellectual disability or cognitive impairment must not be excluded from individual funding arrangements or initiatives under *Your Life Your Choice*. Exclusion of people with intellectual disability or cognitive impairment from these initiatives greatly increases the likelihood that they may be limited in their ability to access appropriate living arrangements and adequate support.

Use of restrictive practices in other environments

Related to this concern is the use of restrictive practices outside of funded disability services, in aged care facilities and boarding houses for example. In its report, *A Review of Queensland's Guardianship Laws*, the Queensland Law Reform Commission (QLRC) also focussed on restriction of the scope of the restrictive practices regime to funded disability services and commented that:

In the Commission's view, it is highly unsatisfactory that the lawfulness of using a restrictive practice in relation to an adult with an intellectual or cognitive disability, and the requirements for the lawful use of such a practice, depend on whether the restrictive practice is being used by a disability service provider who receives funding from the Department of Communities, by a disability service provider who does not receive such funding, or by an individual acting in a private, as distinct from a commercial, capacity.¹⁸

I recently provided a submission to and gave evidence in a hearing to the Senate Community Affairs Reference Committee's inquiry into the *Care and Management of Younger and Older Australians living with Dementia and Behavioural and Psychiatric Symptoms of Dementia (BPSD)*.

In this submission I noted that the regulatory regime for restrictive practices in Queensland only extends to disability services provided or funded by the Queensland Government's Department of Communities, Child Safety and Disability Services, which limits the extent of its protections given that many people with dementia and BPSD are supported through other systems in Queensland, e.g. aged care and/or health.

¹⁷ *Disability Services Act 2006*, s123ZZB

¹⁸ Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws* (Report no 67, 2010) 361

In addition there are a large number of people (an estimated 280) with intellectual disability or cognitive impairment residing in long-stay health care facilities in Queensland. The Office of the Public Advocate has commenced a project aimed at promoting the rights and interests of people with intellectual disability or cognitive impairment residing in psychiatric hospitals, hospitals, rehabilitation services and other health care facilities. The use of restrictive practices such as restraint and seclusion in these facilities is not covered by the restrictive practices regulatory regime in the *Disability Services Act 2006* and the *Guardianship and Administration Act 2000*, nor is it monitored or subject to any type of transparency.

I am also unclear as to the lawful basis for the administration of behaviour control medication (or chemical restraint) to people with intellectual disability (but no mental illness) who are deemed to require involuntary treatment and who are detained in or to Authorised Mental Health Services under the *Mental Health Act 2000*.

Restrictive Practices and Forensic Orders under the *Mental Health Act 2000*

Finally, I would like to raise my concerns about the use of restrictive practices alongside forensic orders under the *Mental Health Act 2000* in lieu of appropriate support arrangements.

I am aware that some people with intellectual disability who are made subject to a forensic disability order are being held in the 'community' in circumstances of detention, ostensibly under limited community treatment arrangements, and are subject to containment under the restrictive practices regime. This seems to me a highly unsuitable arrangement and one that is utilised in lieu of appropriate services for people subject to forensic orders, including 'transitional services'.

Limited community treatment is supposed to enable the transition of a person subject to a forensic order to less restrictive living arrangements, with the gradual aim of the revocation of the forensic order and return to community living and as such, in my view, would generally involve a less restrictive way of living than when a person is detained in an Authorised Mental Health Service or the Forensic Disability Service.

I would encourage the Department of Communities, Child Safety and Disability Services and the Department of Health to review the way in which the *Mental Health Act 2000*, Part 10A of the *Disability Services Act 2006* and Chapter 5B of the *Guardianship and Administration Act 2000* interact in situations such as these as part of the upcoming review of the *Mental Health Act 2000*.

Closing remarks

Thank you for the opportunity to comment on the Discussion Paper: Review of the Regulation of Restrictive Practices in *Disability Services Act 2006* and the *Guardianship and Administration Act 2000*.

As noted throughout the course of my submission, my primary concerns relate to ensuring that the review of the regulatory regime for restrictive practices is appropriately contextualised by also considering the effectiveness, or otherwise, of the complementary systemic reforms that were established to work together with legislation to improve outcomes for people with intellectual disability or cognitive impairment who are subject to restrictive practices.

Inherent to the review process should be a focus on ensuring that the rights and interests of people with intellectual disability or cognitive impairment are upheld, and are central to any considerations for changes to the regulatory regime.

While there is limited data available to objectively measure the success, or otherwise, of these reforms since they were first implemented in 2008, anecdotal information obtained in the course of my research and advocacy activities suggests that legislative change may be less effective than ongoing investment in

building the capability of service providers to implement and integrate a positive behaviour support approach into everyday practice.

In recognising the paucity of data and the associated challenges in making an objective assessment of what may or may not be required to determine the extent to which the intent of these reforms is being achieved, I am of the view that there is an immediate need to improve the monitoring and reporting on restrictive practice use in Queensland, taking into account the full range of factors that have the potential to influence the effectiveness and outcomes associated with implementing a positive behaviour support approach.

While I have noted a number of areas that might be appropriately addressed within the context of reviewing the regulatory regime, I reiterate my support for the safeguards and protections that exist within the legislation as it currently stands and recommend that any proposal that seeks to lessen these protections be immediately dismissed. Furthermore, I believe that there needs to be urgent consideration given to extending these safeguards to ensure that the rights and interests of people with intellectual disability or cognitive impairment continue to be upheld as Queensland progresses toward the implementation of Disability Care.

I am pleased to lend my support to the Department as it progresses this important review in the interests of ensuring that the rights of people with intellectual disability or cognitive impairment who exhibit 'challenging' behaviours are upheld. I would be pleased to make myself available to the Department should there be an opportunity to expand on the points made in this submission.



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