Cerebral Palsy ALLIANCE

# A legislated framework to regulate restrictive practices on people with disability

**Prepared by Cerebral Palsy Alliance**

**For the NSW Department of Communities and Justice**

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## Cerebral Palsy Alliance context

An estimated 34,000 Australians have cerebral palsy (CP). It affects 1 in every 700 births and is caused by a brain injury during pregnancy or shortly after birth and is the most common physical disability. Cerebral Palsy Alliance is committed to positively changing the lives of people with CP and similar neuro-developmental disabilities. With more than 75 years of deep expertise and experience, we have been pioneering treatments, harnessing and accelerating technology and leading global research efforts to fulfil our vision for, and with, people with CP and their families – a global community of an estimated 17 million people.

Cerebral Palsy Alliance is a global leader in disability research through the CPA Research Institute, co-located at the University of Sydney's Brain and Mind Centre, which enables the world's foremost experts to explore prevention, treatment and cures for CP. Founded in 2005, the Research Institute is the world's largest dedicated CP research organisation, employing four of the top 10 experts in the field and published 150 landmark academic papers since 2020. It has significantly contributed to the drop in the prevalence of CP, which has seen a sustained decrease of around 40% from just twenty years ago, when one in 400 children were born with CP.

The CPA Research Foundation is the largest private funder of CP research globally, having provided more than $67 million in grants to 714 projects across 154 academic institutes in 43 countries since 2005, with a specific focus on prevention, treatment and early diagnosis and detection.

We are also a registered NDIS Provider that provides both a range of services: Early Childhood, Therapeutic Supports, Lifestyles Programs, Short Term Accommodation, Supported Employment and Supported Independent Living. We offer Specialist Behaviour Support and Implementation of Behaviour Support Plans which includes the use of Restrictive Practices as prescribed by Behaviour Support Practitioners and authorisation of these practices, we report to the NDIS Commission on the use of all restrictive practices – whether authorised (the majority) or unauthorised.

We are committed to reducing the use of restrictive practices and wherever possible eliminating the use of restrictive practices.

One of the most significant challenges we have faced as an NDIS provider related to this area, is the significant administrative compliance burden in meeting our legislative requirements under the NDIS (Provider Registration and Practice Standards) Rules 2018, NDIS (Restrictive Practice and Behaviour Support) Rules 2018 and the NSW Government Restrictive Practice Authorisation Policy and Procedural Guide. In particular, there are many factors and different parties that impact on the ability to support people with complex behaviours including: funding, behaviour support practitioner quality and capacity. Where there are delays in being able to obtain

authorisation, the reasons may be varied but it is the implementing provider that is held accountable for these gaps. To support Cerebral Palsy Alliance in the areas of Specialist Behaviour Support and Implementing Behaviour Support Plans, we invest in a Safeguarding Practice Team and Senior Consultant for Behaviour Support – this is a headcount of approximately 3.1 FTE.

While we are supportive of improvements to the quality of behaviour support plans and ensuring that there is appropriate oversight of restrictive practices, we are concerned that an area that is already highly regulated may experience additional changes that increase the administrative burden of compliance – it should be carefully considered how the data, that providers in NSW are already providing, can be utilised to inform the Senior Practitioner, rather than requiring a *new* data set to be provided.

The consultation paper lacks information that would support a better understanding of the proposed approach that would be taken; we recommend that as a next step a greater level of detail is provided for review and engagement with key stakeholders.

We note the proposed changes around consent and recommend that people with disability are engaged in developing the proposed approach. It is important to consider – in line with other DRC recommendations, how supported decision making could be incorporated to include people in the decisions being made that will impact them.

Please see our responses to the specific questions as outlined in the consultation paper: a legislative framework to regulate restrictive practices. Where the questions are not relevant to the service Cerebral Palsy Alliance provides, or the profile of the participants we support for example out of home care, or within the justice setting, we have chosen not to provide a response.

## Our response to the Consultation Paper Questions

***Question 3****: What issues and challenges are raised by there being different frameworks for the authorisation of restrictive practices in the disability service provision setting and the aged care setting?*

Ultimately it adds to the confusion for participants/families/practitioners and service providers.

We recommend that there is one single framework guided by clear legislation/policy that identifies what is and what is not a restrictive practice. The human rights principles are universal and should not discriminate based on setting. However, there may be a need to provide additional information and clarification around exceptions to the authorisation rules.

As an example, if an NDIS participant in a SIL service has a dementia informed plan, could consideration be given to reviewing them under the Quality of Care principles; so this is clear for behaviour support practitioners when developing a plan.

A person with disability should be no different in the framework for restrictive practice regardless of the setting. Aged care and disability providers should have the same principles around the use of Restrictive Practices.

***Question 4:*** *Do you support legislation requiring that restrictive practices on NDIS participants in the disability service provision, health, education and justice settings should be governed by the principles recommended by DRC Recommendation 6.35(b)?*

We are broadly supportive of the principes recommended by the DRC; however, we question the change from the current system to the proposed Senior Practitioner system. We would respectfully point out that the DRC had no representative with current operational knowledge of disability service provision.

There is a lack of detail in the consultation paper as to what the proposed process would require – further detail would support a better response to this question. We are concerned about how this is going to be operationalised and delivered without further complications to the process and delaying of authorisation outcomes.

In particular:

- How would an Office of the Senior Practitioner be staffed without removing the most experienced practitioners to that office from the sector?
- How would this be different from the current model where trained Independent Specialists are attending panels and supporting the scrutiny of decisions being made?
- Why is it that NSW DCJ has difficulty recruiting Independent Specialists in the current system? Could this be addressed?
- How would the Senior Practitioner be able to oversee the sheer amount of practices being used in the State?
- How would a partially delegated model work regarding the cost of salary for an APO? Would the organisation have to fund this or would funding be coming from DCJ or NDIS, as this would be a full-time position within larger organisations?

***Question 6:*** *Should a legislative framework prohibit any practices? If so, which practices and in which settings?*

Any practices already identified by the NSW RPA Policy and NDIS Quality and Safeguards Commission as prohibited practices and High Risk of Harm practices should be prohibited in any of the settings where people with disability are supported.

***Question 7****: Do you agree that:*

- *the framework should use the NDIS definitions of restrictive practices?*
- *the Senior Practitioner should have the power to issue guidelines that clarify how the definitions apply in different situations*?

Yes, we are supportive of the framework using the NDIS definitions of restrictive practices.

Yes, we support the Senior Practitioner having the power to issue guidelines. We question whether this is effectively already in place in the form of the NSW RPA Policy and guidelines?

Under the current approach there is also valuable guidance from the Independent on the panel. Could consideration be given to the Senior Practitioner advising Independents to support consistent approaches and discussions to meet the clinical framework and define the operational collaboration and consultation on the implementation of restrictive practices?

***Question 8:*** *What role should the Senior Practitioner play in regulating behaviour support plans?*

*For example:*

- *Should the Senior Practitioner have the power to prescribe additional and/or more detailed information for inclusion in the BSP? If so, what information?*

It is unclear how this is different to the current BSP Positive Behaviour Support Capability Framework and the NDIS Behaviour Support and Restrictive Practice Policy? Should the role of the Senior Practitioner be more aligned to the NDIS Policy with regard to safeguarding, compliance, capability building, evidence informed practice and have some sort of educational role for providers to ensure quality provision for participants with restrictive practices?

If the Senior Practitioner model is adopted, it is expected that the feedback to practitioners would be similar to now when there is information missing or inadequately presented in the BSP. For instance, if information pertaining to the RP is incorrect, misleading or incomplete, and the links to the behaviour of concern and/or PBS strategies, including FERBs is missing, or if there are gaps in the FBA. This is already done to some extent within the current system, but could be more streamlined and consistently addressed, though this takes time, and the Independent Specialists would need to be compensated for the time this may take.

- *Should the Senior Practitioner have the power to require a behaviour support practitioner have certain qualifications and the Senior Practitioner's approval before they can prepare a BSP which will be used to authorise the use of a restrictive practice? If so, what should the additional qualifications and criteria for approval be?*

No, this is the role of the NDIS Quality and Safeguards Commission to monitor this through their registration process. If there are gaps in the current process, we recommend that these are improved rather than create a duplicate state-based process. However, when submissions are being made, including the details of the author of the BSP, we recommend that there should be a requirement to declare what level of registration the main author has, and if a core practitioner, who the clinical supervisor is.

- *Should there be any specific provisions relating to consultation in the development of a BSP, in addition to the requirements in the NDIS Rules?*

No, NDIS Quality and Safeguards Commission's requirements are appropriate. However, as part of the authorisation process it should be checked that appropriate consultations have occurred in the development of the BSP.

***Question 9:*** *Is there anything else the proposed framework should do to improve the quality of BSPs?*

No, this is the role of the NDIS Quality and Safeguards Commission. The proposed framework should focus on RP authorisation and adherence to the identified principles.

The Senior Practitioner is not the operational subject matter expert, they are the BSP expert and clinical advisor for restrictive practices and their role should align with the NDIS QSC requirements and support NSW Behaviour Support Practitioners to provide a BSP that is of quality, that is event based and aligns with the reduction and elimination of Restrictive Practices.

***Question 10:*** *Should APOs be empowered to either:*

- *authorise particular categories of restrictive practices without separate Senior Practitioner authorisation (a partially delegated model). If so, what categories of restrictive practices should be able to be authorised by APOs? Should these be prescribed by legislation, or through class or kind orders?*
- *provide preliminary approval of restrictive practices, with final authorisation provided in all cases by the Senior Practitioner (a two step model)?*
- *What would be the benefits and risks of the above models?*

*Partially delegated model*

There is benefit in an APO with permission to authorise restrictive practices, however this may also introduce concerns about the integrity of this process due to potential conflicts of interest. There would also be implications financially for providers in supporting a role (possibly multiple roles depending on the size of the provider) that is specifically designated to the RP authorisation process.

The APO could have designated authority to authorise in the RP authorisation process (with the independent as a safeguard) with the defined criteria to authorise all RP (as defined currently in DCJ legislation and NDIS QSC requirements). It is assumed the current DCJ policy and procedures and definitions of the Convenor role is equivalent to the APO. Currently there are providers that have developed RP panel convenor / independent notes/checklist that meets all the requirements from the NDIS QSC in the reduction and elimination - perhaps these should be considered for review in the consultation. These documents could be overseen by the Senior Practitioner and agreed in collaboration with providers who are required to facilitate RP panels.

If the APO is a standalone role and there is no involvement of an independent, we suggest that they can only approve restrictive practices on an interim or emergency basis. Even in the current model with Interim BSPs being approved by an authorised officer, there are significant risks if the authorised officer does not have the knowledge, experience or qualifications to make those decisions. All types of RPs have significant risks and allowing APOs to independently authorise any of these practices would be of concern.

*Two step model*

If the Senior Practitioner proposal is implemented, a preliminary authorisation by APO and final authorisation by the SP would provide additional safeguards around any conflicts of interest or lack/variance of knowledge from APOs. Currently,

implementation providers rely on the expertise and independence of the Independent Specialist.

*Benefits and Risks*

Risks of the two-step model would be the time for authorisations. The partially delegated model would be quicker but may increase the risk of practices being authorised or not authorised without proper scrutiny from a third party independent from the implementation provider. The most used practices, types of Environmental Restraint and Chemical Restraint, carry significant risks to the person's human rights and the decision process should not be watered down (even though the model suggests that the Senior Practitioner can audit these practices).

For either model there would be a financial cost to providers who in many cases are already struggling financially – meaning the additional headcount of employing an APO either as part of the organisation or contractor is a compliance viability risk to the organisation, unless funding is being provided by NDIS or DCJ for such position.

***Question 12:*** *Should APOs be required to be employed by a single provider? Or should APOs be permitted to be consultants to a number of providers? If so, what safeguards should there be in relation to this?*

This is difficult to answer as it is unclear who is required to fund this role, we note the consultation paper implies this is an unfunded expense to the provider.

We suggest APO's could be employed/funded by DCJ, like current DCJ independents. The APO could work for the provider however when working on RP panels and preparation, training etc, like the DCJ independent they should be employed by the state requesting them to work in accordance with the legislation. The APO should be provided ongoing training (similar to the DCJ independent) to consider the operational impact and NDIS QSC requirements and situations that may need additional consideration when authorisation RP's. The provider should be able to nominate several APO's and be assessed with agreed criteria from DCJ to be eligible to be an APO.

If the APO is employed by a single provider there is a potential conflict of interest for the APO to make decisions to meet legislative timing requirements or satisfy staff that may not be in the best interests of the participant. The ongoing inclusion of independent specialists would help to mitigate this risk.

***Question 13:*** *Do you support the proposed duration of authorisation and emergency use proposals for restrictive practices?*

We are supportive of the proposed duration of authorisation (12 months maximum length), as currently is in place. We also support the requirement of providing information about how the application would need to describe the steps taken to reduce the use of restrictive practices over the previous period, progress in doing so, why restrictive practices are still required and any new measures to reduce their use.

The emergency use proposal appears problematic as it does not align with NDIS (Restrictive Practices and Behaviour Support) Rules 2018 where the requirement is to develop an Interim BSP within a month, which then will need to be authorised by the authorising officer. We suggest that changes to this process should be made by NDIS Quality and Safeguards Commission, not DCJ.

***Question 14:*** *Are there any additional grounds on which the Senior Practitioner should be able to cancel an authorisation?*

The Senior Practitioner will not have operational knowledge and should only cancel authorisation when consultation and collaboration is sought from the panel, APO and independent on the RP outcome. This should not be a sole decision.

***Question 15:*** *Should authorisation decisions:*

- *be open to internal review?*
- *be reviewable at NCAT?*

Yes, there should be an avenue for internal review of decisions.

In addition, if there are concerns related to authorisation of a practice that have not been resolved these could be reviewed by NCAT. Noting that it would be important that the NCAT Officer is knowledgeable and skilled in PBS and use of Restrictive Practices. They must also understand the NDIS (Restrictive Practices & Behaviour Support) Rules 2018.

***Question 16:*** *Should rights to seek review be limited to the person or a person concerned for their welfare? Should the service provider have a right to seek review of a decision not to authorise a restrictive practice?*

Participants and/or their representatives and the implementing provider should be able to seek a review to authorise/not authorise a restrictive practice when there is a real or perceived risk of harm to the person and/or others.

There may also be significant WHS issues that give service providers cause to seek a review of decisions made not to authorise a restrictive practice and it would be advisable that this avenue is available to them.

***Question 17:*** *Should a person have a right to request the service provider review the BSP at any time?*

Yes, noting there can be challenges when there is a lack of funding to achieve this.

***Question 18:*** *Should the Senior Practitioner have complaints handling and investigation functions either on receipt of a complaint, on its own motion, or both?*

It is understandable that the Senior Practitioner may receive complaints and requires an approach to deal with these. The scope and pathway for this should be clear to avoid double up with the NDIS Commission. For example, complaints should relate to the authorisation or non-authorisation of restrictive practices and/or misuse of restrictive practices.

Careful consideration should be given to how complaints functionality could be integrated with the NDIS Commission and any follow up with providers including investigation needs to consider the impact of each other's functions. For example, if the Commission is running a campaign around restrictive practices, the burden to providers would be significant if DCJ commenced its own motion actions around a similar area. Ideally there would be arrangements in place for appropriate sharing of information between regulators and efficient requests from providers, rather than duplicated campaigns that increase administrative burden for providers.

***Question 19:*** *Do you agree the Senior Practitioner should have the proposed powers to respond to misuse of a restrictive practice?*

Yes, considering the Senior Practitioner's role will be (if adopted) to oversee the authorisation process and also authorise restrictive practices, it would be expected that this office should be able to investigate allegations of misuse of restrictive practices.

***Question 20:*** *How should interaction with the NDIS complaints framework be managed?*

There needs to be a clear framework and understanding (e.g. MoU) between the Senior Practitioner and the NDIS Commission. If there is to be a separate complaints framework any duplication of scope should be avoided so that providers are not responding to multiple regulators around the same issue.

It would be important be make it clear to participants, their representatives and service providers in a simple way what the appropriate pathways is to raise their concerns.

***Question 21:*** *To which bodies should the Senior Practitioner have the power to share information and in what circumstances should the Senior Practitioner be permitted to share information?*

The NDIS Commission and NSW Police and with any other body that the participant and/or with whom their legal representative have given consent to the Senior Practitioner to share information.

***Question 22:*** *Are the means by which the Senior Practitioner would have visibility of the use of restrictive practices by NDIS providers proposed in this Paper sufficient? If not, what additional information should providers be required to report to the Senior Practitioner? How can reporting burden to the Senior Practitioner and the NDIS Commission be minimised?*

In the proposed future model, we understand it would be appropriate to provide the Senior Practitioner with visibility of the use of Restrictive Practices. We request that DCJ considers whether information sharing between the NDIS Commission and DCJ could be achieved to prevent providers needing to report the same information to multiple regulators. Should this not be possible legally, we request that DCJ aligns its requirements to what is already provided to the NDIS QS Commission so that an extract of this information can be shared with DCJ to streamline the process.

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