Advocating for people with intellectual disability and their families

National Disability Strategy Governance and Engagement Section
Department of Social Services
GPO Box 9820
Canberra, ACT 2601

By email: disabilityreform@dss.gov.au

30 October 2020

Re: National Disability Strategy Position Paper submission

STAR Victoria is an independent Victorian-based advocacy organisation, established in 1970. We are dedicated to working with people with intellectual disability and their families, to speak up for their rights, to fix the laws that stop them from living fully inclusive lives of their own choosing and to change community attitudes towards people with intellectual disability.

We welcome the opportunity to make a submission to the National Disability Strategy Position Paper. In summary, we note that the position paper outlines the critical features that require addressing to achieve full inclusion for people with disability. We also note there needs to be more targeted funding to service organisations to fill representation gaps for people with disability and that continued cultural change is necessary to achieve systemic change.

We make the following recommendations:

RECOMMENDATION ONE:

Increased support services be funded to realise full inclusion for people with disability and meet Australia's obligations under the United Nations Convention.

RECOMMENDATION TWO:

A presumption of capacity for people with intellectual disability should underpin all decisions and interactions in all service provision.

RECOMMENDATION THREE:

The final Strategy should use empowering language that reverses the onus on people with disability, and their families and advocates, to prove their worth and capacities.

RECOMMENDATION FOUR:

All tiers of government must provide accessible information for people with intellectual disability.

RECOMMENDATION FIVE:

The Strategy should expressly recognise the nexus between the non-government sector and self-advocacy and advocacy groups and their families and set aside adequate ongoing funding to continue systemic change.

RECOMMENDATION SIX:

Quantitative data collection and analysis be informed by the experiences of people with intellectual disability.

RECOMMENDATION SEVEN:

More frequent and targeted action plans must be underpinned by contributions from affected people.

RECOMMENDATION EIGHT:

Community engagement must be funded to meet the diverse needs of the community.

Our comments are described in detail below.

STAR

STAR Victoria Inc. (STAR) is a community organisation that advocates on a statewide basis for the rights of people with an intellectual disability and their families.

Inclusion, equitable treatment and access to justice underpin the advocacy work of STAR.

STAR was established in 1970 when parents of people with an intellectual disability recognised that, whilst trying to improve the circumstances for their own children, it was essential to change community attitudes to intellectual disability.

Then, as now, we are committed to equity and full community inclusion and participation for people with intellectual disability, from pre-school through to adult education and employment, recreation, and all aspects of ordinary life. We do this by supporting families and self-advocates with information and support.

STAR seeks to drive legislative change that places at the heart of Victoria’s legal framework the rights of families and the human rights of people living with an intellectual disability without systemic, economic or structural restraint.

STAR is a member of Disability Advocacy Victoria, the peak body of independent disability advocacy organisations.

While all aspects of inclusion are fundamental to people living with intellectual disability enjoying full citizenship rights this submission will focus specifically on;

- the rights of parents with intellectual disability; and

- rights to inclusive, lifelong education.

STAR employs an integrated model of advocacy in all our work to pursue systemic change and give voice to families and people with intellectual disability.

STAR welcomes the opportunity to make a submission to the National Disability Strategy position paper.

THE 2010 – 2020 STRATEGY

The intent of the six key outcome areas of the 2010 – 2020 Strategy was to set out a policy framework that, when implemented, operated to give full rights to people living with disability. Policy documents rarely exist in isolation and that is particularly so in respect to governmental action for people with disability and their families. Myriad policy approaches have informed action to improve the lives and access to information and support for people with disability and their families. Yet as we move into the third decade of the 21st century there is more work to be done to achieve full rights to community access and participation for some of our most vulnerable citizens.

Over the life of the Strategy the National Disability Insurance Scheme (NDIS) has been implemented. A founding principle of the NDIS was the recognition that provision of supports and funding for people with disability was inadequate[1]. Yet research on the NDIS demonstrates it has yet to realise its full potential. Complexity and poorly targeted funding remain a barrier to the full inclusion of people with disability as evidenced through participants being unable to obtain necessary supports, having to navigate complicated administrative processes and crucially, that people without support systems find it difficult to advocate for their needs[2].

At STAR our intake service is regularly managing advocacy requests for people who are unable to obtain services due to long waiting lists. Service organisations are not funded sufficiently to employ the necessary number of skilled and qualified staff to case manage the complex needs of people with disability.

The development and implementation of the NDIS has in part been managed through the Council of Australian Government (COAG) arrangement. The COAG process brings together federal and state ministers and other key decision makers across states and territories, including local government representatives on invitation. Established to oversee significant national issues COAG has taken a lead role, via the Disability Reform Council[3], on the implementation of myriad large scale reforms.

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[1] Productivity Commission, (2011). Disability Care and Support. Accessed 9 October 2020, <https://www.pc.gov.au/inquiries/completed/disability-support>

[2] Warr, D, Dickinson, H, Olney, S, et. al., (2017) Choice, Control and the NDIS, Melbourne: University of Melbourne. Accessed 9 October 2020, <https://socialequity.unimelb.edu.au/__data/assets/pdf_file/0010/2364499/Choice-Control-and-the-NDIS-Report-Melbourne-Social-Equity-Institute.pdf>

[3] DSS. n.d. Disability Reform Council. Accessed 9 October 2020, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/government-international/disability-reform-council>

In May 2020 Prime Minister Morrison announced COAG will be replaced with the National Federation Reform Council (NFRC)[4]. It was also announced that the current terms of reference and the existence of the Disability Reform Council, are being reviewed[5]. To date it is unclear what functions the NFRC will undertake, in what circumstances, and if it will continue to oversee large national projects such as the NDIS and advocate for change and reform of disability services. If the replacement COAG no longer functions to bring responsible local, state and federal decision-makers together a replacement body capable of coordinating critical services on the same terms as COAG is necessary.

The next generation Strategy must address the systemic issues that remain as barriers to people living with disability. A key action is funding more advocacy services to ensure all voices are heard and that substantive, not symbolic, change underpins the next decade of disability support.

THE 2020 POSITION PAPER

STAR welcomes the commitment to developing a Strategy ('the Strategy') that creates 'the structures and practices through which people with disability can understand and exercise their rights across all domains' (pg. 5). In our key areas of advocacy – support and information for families, parental rights for people with intellectual disability and equitable access to lifelong education – systemic exclusion continues.

STAR embraces the turn to full recognition of people living with disability and supports the overarching commitment of the next national disability Strategy of:

An inclusive Australian society that enables people with disability to fulfil their potential as equal members of the community.

For STAR, full accessibility to all areas of life is necessary to achieve real inclusion. Full accessibility not only requires voices to be heard but also adequate funding for case management, specific data collection and positive representations of people in the community. STAR has a particular focus on the right of parents with intellectual disability and the rights for people with intellectual disability to access mainstream school and lifelong education. Our self-advocates have had a range of life experiences. Some have been treated well throughout their lives, others have been unsafe in their home, residential, school and community lives.

Key to STAR's advocacy work is making our communities safer and fairer and in doing so, driving positive social and economic outcomes for families and people with intellectual disability. This can only be achieved with targeted, inclusive service provision across all aspects of life, underpinned by

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[4] COAG. Accessed 9 October 2020, < https://www.coag.gov.au/>

[5] PMC. Accessed 15 October 2020, <https://www.pmc.gov.au/domestic-policy/effective-commonwealth-state-relations>

a positive culture of participation for people with intellectual disability. This extends to presenting positive visual representations of people with intellectual disability participating across all facets of life underpinned by whatever supports are necessary to achieve full inclusion.

In their review of the current Strategy Davy et.al (2019[6]) find there needs to be better integration with grassroots groups and all tiers of government to develop evidence based illustrations of how disability services are best implemented. STAR provides support to families and for self-advocates to give voice to their experiences to fully engage in the community. We do this via our Committee of Management that consists of all people committed to the purposes of STAR, people with intellectual disability, interested community members, and a small paid workforce. This means that families and self-advocates are central to the way we approach our work.

The Disability Royal Commission[7], underway during the consultation phase of this next Strategy, is highlighting continual systemic failures in the disability support sector. Established to examine abuse, violence and neglect of people with disability, since COVID-19 has struck the Commission has extended its remit to examine how the sector has managed the pandemic. The Commission notes that additional supports for people with disability have been provided however, they are linked to NDIS recipients leaving a gap for people who do not have NDIS supports[8].

The NDIS has been hard fought for by people living with disability, their families and advocates. In part the NDIS is a response to long term underfunding and undervaluation[9] of people and the sector. Research examining how consumers[10] and workers[11] experience the NDIS continues to identify a need for more supports and funding. The COVID-19 pandemic has also highlighted continuing gaps that the new Strategy must address outside the funding and operation of the NDIS.

As acknowledged in the position paper, voices of people with disability remain a crucial feature underpinning decision-making:

> *An essential part of this ten year Strategy is the engagement of people with disability in the further development, implementation and monitoring of progress' (pg. 10).*

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[6] Davy, L., Fisher, K.R., Wehbe, A., Purcal, C., Robinson, S., Kayess, R., Santos, D. (2019). Review of implementation of the National Disability Strategy 2010-2020: Final report. (SPRC Report [4/19). Sydney: Social Policy Research Centre, UNSW Sydney. Accessed 15 October 2020, <https://www.arts.unsw.edu.au/sites/default/files/documents/NDS_Review_Final_Report.pdf>

[7] Disability Royal Commission. Accessed 9 October 2020, < https://disability.royalcommission.gov.au/>

[8] Disability Royal Commission. Accessed 22 October 2020, <https://disability.royalcommission.gov.au/system/files/2020-03/COVID-19%20Statement%20of%20concern.pdf>

[9] Productivity Commission, (2010). Contribution of the Not-for-Profit Sector. Accessed 15 October 2020, <https://www.pc.gov.au/inquiries/completed/not-for-profit/report>

[10] Warr, D, Dickinson, H, Olney, S, et. al. (2017) Choice, Control and the NDIS, Melbourne: University of Melbourne. Accessed 15 October 2020, <https://socialequity.unimelb.edu.au/__data/assets/pdf_file/0008/2598497/Choice-Control-and-the-NDIS.pdf>

[11] Cortis, N., Macdonald, F., Davidson, B., and Bentham, E. (2017). Reasonable, necessary and valued: Pricing disability services for quality support and decent jobs (SPRC Report 10/17). Sydney: Social Policy Research Centre, UNSW Sydney. Accessed 15 October 2020, <https://www.arts.unsw.edu.au/sites/default/files/documents/NDIS_Pricing_Report.pdf>

This engagement also includes the critical role of advocates whose primary focus centres on improving services and thus the lives of people with disability. STAR fills a unique gap in the self-advocacy and advocacy environment. Our specific focus on parents with intellectual disability and their right to be presumed capable of parenting, and lifelong inclusive education for all are significant areas of much needed action and reform.

These voices also need to be heard in the quantitative approach to support services. The position paper sets out a need for data collection:

> *The report will be prepared every two years and will use trend data based on the six outcome areas of the Strategy' (pg. 10).*

Good data informs good public policy. It is, however, the experience of STAR that specific data collection that reflects the lived experience of people, parents and families at the micro level is necessary to drive positive and adequate public policy. Granular level data that presents an accurate representation of how people experience interventions is necessary. This includes having accurate descriptions of data collection terms and definitions. For instance, if a child removed from a parent with intellectual disability is to be cared for 'within the family' it is necessary to further examine this response and question if the birth parent has access to their child, and under what circumstances. For example, are they only allowed supervised visits for a certain number of hours per week, are they involved in decisions regarding their child's well-being and what framework is in place to have as the highest priority the return of the child to the parent? Granular data of this nature fits with Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (CRPD)[12].

THE QUESTIONS

Question 1:

During the first stage of consultations we heard that the vision and the six outcome areas under the current Strategy are still the right ones. Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

STAR agrees the six outcome areas remain priorities. It is, however, our submission that particular emphasis must be placed on realising genuine inclusion within these areas. There continues to be insufficient funding of service organisations to assist people manage everyday life experiences. Waiting lists for people requiring long term, case management as a result of poorly targeted funding continue. At STAR we advocate for people experiencing exclusion across many aspects of life. This

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[12] United Nations Convention on the Rights of Persons with Disabilities (CRPD). Accessed 15 October 2020, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

includes parents seeking access to justice or people requiring behavioural management supports so they may participate in life events.

Systemic inclusion and cultural change require that a presumption of participation and capacity for people living with intellectual disability underpin decision-making through all tiers of government, non-government, business and the broader community. When the broader population educates themselves on the rights to full participation and capacities of people living with intellectual disability, full inclusion can be realised.

The 2010-2020 Strategy set out a particular focus on the rights of parents with disability that are yet to be realised. Whilst maintaining the focus of the current Strategy, further emphasis on specific areas is necessary. For instance, in the existing Strategy Legal Aid Queensland pressed the point of parents with disability:

> We are concerned that decisions to remove children from parents with disability are made on the basis of the disability, rather than on the parent's capacity to parent effectively and appropriately (2011, pg. 38).

In Victoria legislation prevents a child being removed from a parent based on the sole reason the parent has an intellectual disability yet parents continue to experience barriers in their parenting[13]. It is STAR's experience that cultural approaches to a presumed lack of capacity on the part of the parent acts as a proxy for re-introducing discriminatory behaviour, assuming an intellectual disability presents a risk to the child. We have direct and recent experience of this in the advocacy work we undertake with parents who have had their child removed at hospital after giving birth and also throughout the parenting journey.

The existing Strategy referenced this form of different treatment which set out the need for better services for parents with disability:

> Women with disabilities who are parents or seeking to become parents experience discriminatory attitudes and widely held prejudicial assumptions which question their ability and indeed, their right to experience parenthood. They experience significant difficulty in accessing appropriate parenting information, services and support in a host of areas (2011, pg. 49).

Yet a decade on it remains the case that support services are lacking and that more work is necessary to disrupt cultural views of incapacity. Further work is required to ensure compliance with the principles contained within the United Nations Convention on the Rights of Persons with Disabilities ('the Convention').

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[13] Parenting Research Centre, (2019), Hand in Hard Report. Accessed 23 October 2020 <http://www.daru.org.au/wp/wp-content/uploads/2018/10/Hand-in-Hand-Parents-meeting-final.pdf>

Chapter 5 of the existing Strategy sets out how lifelong learning, a further focus of STAR's advocacy work, will be achieved. Specifically, reference is made to the need for discrete learning and development for those providing education services:

- professional development for teachers, school leaders and other school staff
- workshops and information sessions for parents and carers (2011, pg. 57).

Again, STAR continues to advocate for fully inclusive education for people with intellectual disability. Inclusive education as a best practice model achieves three main objectives. First, as argued by Jackson (2003) it is a moral question. Exclusion of any sort serves to create lifelong barriers to full participation and enjoyment of life. Second, inclusion is directly related to our values. When society includes everyone positive cultural change, particularly in respect of acceptance, shifts for the better. Third, policy and curriculum development based on inclusion not only educates people with intellectual disability but contributes to breaking down barriers in other aspects of life. Jackson (2003) further argues that in a review of the international literature on segregation and inclusion overwhelmingly support is found for inclusive education:

> In a recent review of the literature that I did for an international conference on inclusion, I could **NOT FIND ONE** (author's emphasis) research article comparing inclusion with segregation that favoured segregation. Professors and Heads of Education at Australian Universities were written to stating that finding and asking if they knew of any contrary finding. No one came up with a contrary finding. The finding was not challenged by any of the international experts at the conference who indeed agreed with my finding. Similarly, Directors General of Education in all Australian States were asked for the research base on which they recommended segregated schooling. While many referred to government reports, they also could not provide empirical evidence in support of segregated schooling for children with an intellectual disability[14].

Children with intellectual disability have a right to mainstream education with specific support services as necessary. This not only sets the same expectations for children with intellectual disability but builds knowledge among the community that all people are entitled to be included. As argued by Cologon (2019) current debates continue to support inclusive education as the main priority in the delivery of education services and the disrupting of negative attitudes[15].

The new vision and Strategy must deal with these legacy issues in meaningful ways. Prioritising mainstream school for all children beginning their education journey and information and support services to facilitate the movement of students from segregated to mainstream schooling is necessary. Increased funding to advocacy organisations to fill representation gaps is crucial. Too

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[14] Jackson, B, (2003), Should schools include children with a disability, page 3, accessed 8 October 2020, available at <https://www.family-advocacy.com/assets/Uploads/Downloadables/7bbb05fb26/11177.pdf >

[15] Cologan (2019) Towards inclusive education: A necessary process of transformation. Accessed 8 October 2020, available at <https://apo.org.au/node/36129>

many people are still failing to receive long term, case management support to achieve full inclusion.

RECOMMENDATION ONE: Increased support services be funded to realise full inclusion for people with disability and meet Australia’s obligations under the United Nations Convention.

Question 2:

What do you think about the guiding principles proposed here?

STAR supports the inclusion of the principles outlined in the position paper. We note involvement and engagement of people with disability is often discussed. To give life to this commitment genuine engagement via self-advocates, their families and advocacy services is necessary to hear the voices of people with disability. Similarly, greater emphasis on visual representations of people with disability is necessary to reduce stigmatisation. For instance, annual reports across public and private sectors often include diagrammatic representations of percentages of people from non-English speaking backgrounds accessing services. The same process can apply to people with intellectual disability. This serves to acknowledge the provision of services and also reduces stigmatisation when the language of intellectual disability becomes mainstream.

Universal design principles provide a good guide to enhance inclusion. We submit that for the reasons set out in this submission specific reference - written and visual - to people with intellectual disability reinforces recognition of people’s needs and capacities. Assistive technologies in isolation do not achieve inclusion. Building capacity within advocacy organisations to continue to up-skill people with intellectual disability broadens the application and accessibility of assistive technologies. When people are supported to engage in processes affecting their life, better outcomes are achieved.

Overall, these approaches to broadening visibility in written and diagrammatic forms shifts the focus from the person with disability from having to prove their worth and places an onus on the community to learn more about people’s rights to be supported and included. As set out in our response to question one, more work is to be done to address cultural barriers that presume an incapacity with limited access to long term support.

RECOMMENDATION TWO: A presumption of capacity for people with intellectual disability should underpin all decisions and interactions in all service provision.

Question 3:

What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

Article 8 of the United Nations Convention articulates the principles of inclusion that Australia recognises as fundamental to the treatment of people with disability:

> 1. States Parties undertake to adopt immediate, effective and appropriate measures:
>
> a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
>
> b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
>
> c) To promote awareness of the capabilities and contributions of persons with disabilities [16].

Inherent in this commitment is action to address ways in which people with disability are excluded from the full benefits of social and economic participation. A key way exclusion manifests is through the use of language that create distinctions between rights, capacities, contribution and participation in all aspects of life for people with disability. It is our experience that judgemental attitudes of incapacity not only exist in the broader community but in government services where people are presumed to have limited capacity and their need for supports are limited by others.

The Davy et.al (2019) review noted the NDIS has assumed much focus in the previous decade. The NDIS should not detract from other areas of necessary transformation. It is our experience that integration requires far more attention to change attitudes across all aspects of people's lives. We particularly see this in education where attitudes to children with intellectual disability remain limiting. We have initiated a series of training workshops to disrupt these barriers and provide knowledge to parents, educators, local and state government decision-makers[17]. To achieve attitudinal change in the community, initiatives such as this are necessary and that they be resourced and funded to achieve the vision of the draft Strategy.

RECOMMENDATION THREE: The final Strategy should use empowering language that reverses the onus on people with disability, and their families and advocates, to prove their worth and capacities.

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[16] United Nations Convention on the Rights of Persons with Disabilities (CRPD). Accessed 15 October 2020, < https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

[17] STAR Victoria Inc. Accessed 16 October 2020, < http://starvictoria.org.au/abcworkshops/>

Question 4

How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

We support the approach to detailing at a micro level the roles and responsibilities for all tiers of government. Such reporting, produced in accessible formats, will assist in developing in people with intellectual disability the knowledge and understanding of where they can access services. Access to justice is a key area of STAR's advocacy. This is critical for parents who are forced into the child protection and justice system after their child/ren have been removed.

It is our experience that parents are excluded from caring for their child/ren, from decision-making regarding their child/ren and from the supports they rely on to be the best parents they can be. Myriad services and supports exist for parents without intellectual disability to parent well. This support does not always translate to the parents STAR advocates for. The presumption of incapacity all too often shapes the ways in which others with power and decision-making capacity determine risk for child/ren without sufficient examination of the capacities of parent/s.

It is the role of all tiers of government to approach service provision with a presumption of capacity for people with intellectual disability. Accountable decision-makers should have as part of their responsibilities a core commitment to establish inclusive communities. Cultural training should also be extended to direct workers across all government services. Moreover, all tiers of government should be providing information in easy English and other accessible formats.

RECOMMENDATION FOUR: All tiers of government must provide accessible information for people with intellectual disability.

Question 5

How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with disability?

The non-government sector is the closest point of ongoing interaction with people with disability. Advocacy groups such as STAR have direct relationships with people with intellectual disability. Moreover, STAR supports other self-advocacy organisations such as Reinforce[18] and Positive Powerful Parents[19] to ensure their voices are heard in the ways they choose to represent their members. We are able to build professional and supportive environments that enable the voices of

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[18] https://reinforce.org.au/

[19] https://positivepowerfulparents.com.au/

people to be heard. This approach requires funding to ensure the voices of people with intellectual disability are heard by government and business.

The position paper at page 8 addresses the role of the NDIS in participants' lives. While the position paper notes the NDIS is a key resource, as argued previously, more action is required to support people with disability. The NDIS is for necessary individual support but by itself it does not address systemic change necessary for people with intellectual disability. While it might provide funding for people to be supported accessing services such as the justice or education systems, it does not drive attitudinal change in the community. Systemic change is essential to facilitate inclusion and participation in community life. STAR is fortunate that the Victorian Government continues to support advocacy through its Disability Advocacy Program, but this is not the case in other jurisdictions.

Accountabilities of government agencies should be broader than the NDIS. Funding for registered advocacy organisations that empower people with intellectual disability to participate in decisions that impact their lives is fundamental to giving life to the vision of the Strategy.

RECOMMENDATION FIVE: The Strategy should expressly recognise the nexus between the non-government sector and self-advocacy and advocacy groups and their families and set aside adequate ongoing funding to continue systemic change.

Question 6:

What kind of information on the Strategy's progress should governments make available to the public and how often should this information be made available?

We support open and transparent reporting of qualitative and quantitative data. These should be accompanied by illustrations of where barriers have been identified, the impact of how people have been excluded and the steps all tiers of government have taken to address deficiencies. Good examples of the reporting of systemic issues can be found in the annual reports of Ombudsman services and national regulators, such as the Energy and Water Ombudsman (Victoria), or the Australian Competition and Consumer Commission.

The position paper at page 10 specifically addresses data capture. It is our experience that data capture is concentrated at a macro level. The STAR approach to advocacy concentrates on the micro level and specifically putting a human face and story to people's experiences. The cultural problem specifically in respect to parents with intellectual disability also infects data collection. In order to genuinely measure outcomes, data collection methods must be specific to the experiences of people. STAR’s advocacy work with parents with intellectual disability reveals inadequate data capturing processes which disguise the hurt and harm caused by government intervention.

For parents in the hospital setting having given birth, it is our experience that babies are removed from parents with insufficient support and examination of the capacities of parents. While child protection officers may place the baby within the ‘family’ environment, this broad term does not indicate what interaction the parent has with their baby. It is STAR’s experience that child protection services do not adequately support a parent with intellectual disability to care for their child nor support that parent with access visits when the child is taken from them. Under COVID these circumstances have been even more detrimental. We know of parents who have not seen their child for months as supervised visits have not been arranged out of fears of virus spread.

Consistent with our earlier submission we submit that any replacement of COAG must continue the granular collection of data that assess outcomes for people with intellectual disability. The National Disability Data Asset (NDDA) project should report outcomes at the micro level.

RECOMMENDATION SIX: Quantitative data collection and analysis be informed by the experiences of people with intellectual disability.

Question 7

What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time (for example within one, two or three years)?

STAR supports the specific targeting of cohorts within the disability sector using relevant data collection tools and analysis. For reasons outlined previously cultural assumptions can cloud the judgement of services providers across public and private sectors and across all professions resulting in exclusion and harm to people with intellectual disability. Similarly, blunt data collection instruments can also disguise the lived experiences of people with disability. Data collection design must be informed by actual experiences of people with intellectual disability.

Interpretations of data should also be underpinned with qualitative analysis. It is insufficient to simply count the number of supports people are receiving in their parenting or education journeys. This quantitative data must be underwritten by the purpose of supports and analyse the benefits people receive from supports in a timely manner.

Further, the passage of time between data capturing and reporting can result in continuing harm. For instance, when a parent with intellectual disability has their child removed from them in hospital the delay in reporting and following up that person can result in them being isolated from their child for months or years. This harm needs to be addressed first and foremost and not be dependent on data capturing, analysis and reporting. More frequent and targeted reporting gives an opportunity for advocacy groups such as STAR to intervene and provide relevant and timely evidence of the impact of policy and program interventions.

RECOMMENDATION SEVEN: More frequent and targeted action plans must be underpinned by contributions from affected people.

Question 8

How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

A new Strategy that genuinely includes all voices, in accessible formats, is welcomed by STAR. Self-advocates and advocacy groups that support and develop the skills and knowledge of people with intellectual disability are key to ensuring voices are heard and systemic change is achieved.

STAR exists to place people with intellectual disability and their families at the heart of policy and decision-making. Providing examples of how people are excluded and how barriers can be broken down are key to achieving system change. The engagement plan should specifically set out areas of service engagement people with intellectual disability require such as access to justice, housing, parenting support, education and employment. The Strategy must also actively set out how people from diverse backgrounds will be contacted and have their voices heard in decisions that impact their lives.

RECOMMENDATION EIGHT: Community engagement must be funded to meet the diverse needs of the community.

If you require more information or would like to discuss the matters raised in this submission, please do not hesitate to contact Karen Douglas at policy@starvictoria.org.au or 0419 412 401.

Yours Sincerely
STAR VICTORIA

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