DISCUSSION PAPER.
DISABILITY SECTOR ISSUES AND RECOMMENDATIONS.

AUTISM ADVISORY AND SUPPORT SERVICE

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Autism Advisory and Support Service (AASS) are a grass roots not for profit community organization who support families on a daily basis through the journey of having a child with disabilities, especially an Autism Spectrum Disorder. We also offer a multi disciplinary approach to therapies and supports for each individual, depending on their needs and those of the family. This is in line with the true spirit of the NDIS. Choice and Control.

One of our most important roles is that of family support and advocacy for the families we serve. These vulnerable families include:

- Participants with complex and severe disabilities
- Families from culturally and linguistically diverse backgrounds
- Families from low socio economic backgrounds
- Parents who themselves have mental health issues or other disabilities

Three issues are clear and recurrent while performing our family support and advocacy services:

- the lack of collaboration between the three tiers of Government
- the impact of Government departments who silo their funding and
- the lack of staffing and forward planning for the sector.

AASS are passionate about the welfare of the families we serve. This paper reflects the current concerns within the disability sector. We believe our recommendations are simple, cost effective solutions that will see the sector remain viable and sustainable.

Grace Fava OAM

Founder/CEO

Sector	Issue	Recommendations
ALL	Currently, all three tiers of Government do not cooperate or collaborate in order to achieve the best outcome for an individual. There is a push and pull between departments with everyone protecting their funding.	✓ **We need a Minister for Autism on a Federal level and for each State. SA are making great progress with their newly appointed Minister. Other States should learn from them.**
ECEI/NDIS	Children turning 7 years of age have their funding considerably slashed when transitioning to the NDIS for funding. This results in a lack of consistency at a time when therapies are starting to have a positive impact on the child.	✓ **Planners and LAC to read the reports by professionals working with the child and take on their recommendations.**
NDIS	Families who have no capacity to manage a plan due to a lack of education, mental health issues or English not being a first language should be offered support coordination to ensure timely and meaningful supports are put in place and effective use of the NDIS plan. Most families are NOT offered this support, instead being told by LAC's that they will support them. LAC's have such high KPI's and are not easily reached so are unable to support families in this way.	✓ **Support coordination funding to be a priority for families who need support to build capacity.** ✓
NDIS	A backlog of service providers waiting to become registered with the Quality Safeguards Commission and the NDIA.	✓ More staff required in the administration area to review and process registrations
NDIS	A high number of service providers who offer face to face services who are not NDIS registered such as allied health, respite, day programs, therapy assistants, exercise physiologists, community supports and other support workers	✓ **These providers should all be registered with the NDIS either under their own name or as part of a consortium to ensure accountability and consistency with quality of services and supports provided.** ✓ Registration will also ensure they are accountable to the NDIS workers check and NDIS Quality Safeguard Commission (QSC) requirements, especially with regards to restrictive

		practices and covid safe practices such as immunisations.
NDIS	Service providers who over charge, do not offer correct services and take advantage of vulnerable participants.	✓ Only allow service providers who are registered to offer NDIS funded services. ✓ More administration required in the fraud section of the NDIA ✓ **More power to the QSC to train providers where they require assistance in procedures and reporting**.
NDIS	A lack of experienced Allied Health Professionals A lack of student placements to offer experience in a variety of settings	✓ Collaboration with the Universities and High schools to have a recruitment drive. ✓ **Paying providers a small supervision fee to host student placements within their service such as with nursing and physiotherapy.** ✓ Mandatory 1 year practical placement in a variety of settings for students in their final year to offer them diverse experience in service provision.
NDIS	A lack of understanding on the roles and responsibility of NDIA and NDIS QSC	✓ More accountability and understanding in each department as to their roles and responsibilities. ✓ A point of contact who can guide people to the correct department for their issue/enquiry.
NDIS	Too many plans have funding slashed without cause. On rejection of a review, they are sent to the AAT, costing the NDIA more than the initial request for supports. The legislation calls for value for money and having solicitors stretch out cases for individuals in need is not value for money.	✓ Only keep the AAT as an absolute last resort where mediation is not successful. ✓ **Planners and review staff to read all reports and be experienced in the needs of a range of disabilities.** ✓ If there is no experience, then planners and LAC's MUST be meaningfully trained in these areas.

NDIS	Inconsistencies with information between what is relayed to the LAC and what is received by the planner. This leads to insufficient information making its way to the decision maker.	✓ **A holistic approach should be made when gathering information on participants.** ✓ Allocation of funds should be made in partnership with participants taking into account their situation and goals.
Health **Mental Health**	Many parents rely on community-based Doctors as they cannot afford a private Doctor. Most Doctors have a fee for service model that is out of reach for many. Once a child has a formal diagnosis, they are often not able to readily access pediatric supports from community health. Once they turn 18, they are sent to a psychiatrist as there is no other appropriate specialist to take on their case if they are on medication.	✓ The need for more developmental Pediatricians and psychiatrists who understand complex disorders and who bulk bill both in private practice and in the health system. ✓ **NDIS to fund Psychiatrists when the issue is related to a participants disability.**
Health **Mental Health**	Families are not able to change local area health services if they are unhappy with their treatment and/or the clinicians involved with their care.	✓ **The ability for families to choose their community health practice by crossing LGA boundaries.**
Health **Mental Health** **Education**	Long wait lists for assessments in community health. Most families cannot afford an assessment from a private practitioner.	✓ More Psychiatrists/Clinical Psychologists/Paediatricians recruited from Universities with training in this area. ✓ **A well trained mental health team who have appropriate resources to provide timely assessments.** ✓ The capacity for school counsellors to offer more assessments than just IQ and functional capacity. Eg Autism, ADHD etc.
Health **Mental Health** **Police** **Disability** **Education**	There is a lack of understanding of what is mental health and what is a person in distress who happens to have additional needs. Many times people with additional needs with health issues are placed in Mental Health Emergency as there	✓ Training for all staff on mental health/intellectual disability and Autism across all sectors ✓ **Better staffing in hospitals to avoid "tick and flick" attitude.**

	is a preconception that the needs are not health related. <u>The families are not listened to.</u> If a person arrives at hospital after being sedated, they are deemed safe to have the mental health section removed and discharged home without proper consent or consultation with the family, taking into account risks and the amount of times they have presented with the same issue.	✓ Independent Liaison person to meet the patient on arrival at the hospital ✓ Patient to be offered an advocate to help them speak up for their needs. ✓ **A holistic approach to look at the needs of the family as well as the patient. This is especially important when considering discharge.** ✓ If a person presents more than twice for the same issue they MUST be admitted and offered medical investigations. ✓ Transparency for all families so they are not ignored, and their needs are taken into account. ✓ **The formation of safety net organizations who are available 24/7 to assist and support when families are in crisis.** ✓ Discharge papers to be handed to families on discharge. ✓ The capacity to question actions and information noted on the discharge papers, and for these to be edited accordingly.
NDIS	Participants who are palliative as a result of their complex disabilities will die before accessing timely and meaningful services, supports and equipment, resulting in death without dignity and parents fighting a system in their loved ones last days instead of cherishing final days and moments of life.	✓ **A separate pathway to expediate NDIS needs, be they supports or equipment BEFORE so they can be comfortable and die supported and with dignity.**
Health **Mental Health**	Presently all hospitals come under a local area health service. This creates more bureaucracy and administration. This funding can be better used to hire medical staff within the hospitals to better serve the community needs.	✓ **Each hospital to be governed in their own right** ✓ Remove all local area health service districts ✓ Collaboration between hospitals for specialties while being able to accommodate the needs of their immediate community.

Mental Health	A shortage of Psychiatrists who can work with individuals with Complex Needs.	✓ **A recruitment drive attracting Psychiatrists from overseas.** ✓ Compulsory student placements in a variety of mental health settings including where disability and mental health are comorbid conditions. ✓ Appropriate and compulsory training for all levels of mental health workers.
Mental Health	A lack of inpatient facilities that are not locked and take a holistic, trauma based approach to supporting the whole family.	✓ **The OASIS centre which is part of the Murdoch Childrens Hospital in Victoria is an example of what should be the foundation of support in NSW. I know we can expand on their model to make it an appropriate, holistic setting.** ✓ **I have brought this to the attention to the NSW Minister for Health and Mental Health in the past. Nothing has resulted from this.**
Education	A lack of appropriate settings for the number of students coming through the system. Many are placed in mainstream where the environment is not conducive to their learning needs. Presently the Principal has the final say on placement of units in their school. A lack of reasonable adjustments are not made within the classroom in cases leading to students not being able to fulfil their academic potentials.	✓ **Every school MUST host a variety of support units in their school.** ✓ Principals to be reminded that they are there to serve the community needs and ensure appropriate placements are made for all students, not just those who are academically minded. ✓ Support from the Department once units are developed to furnish appropriate spaces such as sensory rooms. ✓ Abolish Local Schools, local decisions where it comes to supporting students with additional needs. ✓ More power to regional staff to step into a school to offer supports and training. ✓ **Yearly education to all staff on the disability standards, professional development in**

		areas of need within the school, consistency across the board for all teachers to understand and follow through with reasonable adjustments and individual learning plans. ✓ **Principals to reapply for their position every three years. The panel they apply to should include a representative from an NGO who has no affiliation to the school, a member of the Department and a parent from a different school.**
Education	There have been no new Early Intervention classes formed in NSW in the past 20 years, despite the increase in need. Research shows that early intervention is the key to success. Many children miss out on this early intervention pathway prior to school as a result. There are many cases of child care centres expelling children from their centre/preschool without requesting support or making accommodations.	✓ **Each school to have an early intervention classroom.** ✓ **Stricter laws and processes for centres who do not make adjustments and accommodations for children with additional needs.**
Education **NDIS**	Principals not allowing therapists into schools leading to poor outcomes. Therapists can better support students in an environment that is not always conducive to their needs and offer positive strategies to teachers.	✓ Principals to make accommodations for therapy to occur at school at least twice a month.
Education	There have been many instances where families do not feel heard by the school, they feel intimidated and feel that the school is trying to move their children from the school. There have been many instances where suspensions and expulsion have been placed on the child, and the school have not made any adjustments to how they accommodate the students needs in line with policy.	✓ **Each school to have an independent liaison person to resolve issues within the school and act as a bridge to positive partnerships between family and school.** ✓ A review of the suspension policy and processes. Suspensions for students with additional needs is almost never the answer. ✓ If a student is suspended the liaison person will ensure they

	Parents will go to the region. In many cases parents feel the regional staff are biased towards to school.	are not disadvantaged in any way. ✓ School work will be given to the family and support will be offered to the family.
Education	There are schools who give rolling suspensions to students with complex needs. They say it is to look at options and resources. In the meantime, the student and family are disadvantaged. This process is a vicious circle as many students do not have the capacity to understand why they cannot go to school and for those who enjoy home better, they will then duplicate the behaviours to stay at home.	✓ Review the suspension policy, especially for students whose disability does not allow them to have control over their actions. ✓ Review of the behaviour support processes for students with little or no capacity to understand consequences. ✓ **Opening more support units to accommodate the complex needs of these students who require more support, patience and understanding.** **Suspensions should not be needed to add weight to an access request for a more specialized setting.**
Education	The culture and experiences within a school determine the outcomes for students with complex needs. There is no consistency or process for Principals to follow. Each Principal is in control of their own school. While this may work with staffing issues, it does not work with outcomes for students with additional needs.	✓ The introduction of an independent liaison person per above. ✓ Standards and processes that Principals must adhere to, to offer consistent experiences for all students and families in all schools. ✓ More transparency in the actions of Principals in dealing with suspensions, expulsions and partial attendance. ✓ **Principals to reapply for their position every three years. The panel they apply to should include a representative from an NGO who has no affiliation to the school, a member of the Department and a parent from a different school.**
Housing **NDIS**	Many families who have children with complex needs live in the Department of Housing accommodation. Many times the homes are inappropriate for the	✓ **An incentive for developers to build appropriate social housing for this cohort for people.**

	needs of the child. EG living in a top floor unit where children with Autism will potentially jump, and homes with no fencing for families whose children abscond. The options for young adults who do not attract NDIS funding are very limited. Many are at risk of homelessness and the options for them are not appropriate for their needs. Eg hostel with ex prison inmates, large group homes where they are vulnerable to noise and their personal safety.	✓ An easier process for NDIS and non NDIS participants to access timely and affordable homes, especially in times of crisis. ✓ **Funding of more advocates** who specialize in these areas to offer meaningful and timely supports.
DCJ	Lack of experienced staff Poor communication with stakeholders High number of cases per person Poor decisions made, putting vulnerable children at risk Lack of accountability.	✓ The need for more proactive involvement as opposed to reactive and punitive involvement by introducing more supports to families in the early stages of engagement. ✓ **DCJ to draw immediately on resources to support the family as opposed to reacting to crises.** ✓ **DCJ should be a safety net for families so their issues do not become crises.** ✓ Organizations who are contracting services for DCJ must have yearly training in their roles and responsibilities, transparency in the supports offered, consistency in their supports and stop duplicating services based on what their service network offers. ✓ Employment of only qualified and experienced (or well trained) officers. ✓ Case workers and contractors MUST have knowledge and understanding of a range of disabilities per the cohort of families in their areas. ✓ Discharge of families from the service must be looked at by a panel, not just a worker who has KPI's to meet.