Submission No 13

INQUIRY INTO FOUNDATIONAL AND DISABILITY SUPPORTS AVAILABLE FOR CHILDREN AND YOUNG PEOPLE IN NEW SOUTH WALES

Organisation: Autism Advisory and Support Service

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DISCUSSION PAPER. FOUNDATIONAL AND DISABILITY SUPPORTS FOR CHILDREN AND YOUNG PEOPLE IN NSW.

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.

We work at the coal face of the sector, across multiple settings with some of our communities most at risk families. These vulnerable families include:

- Participants with complex and severe disabilities
- Families from culturally and linguistically diverse backgrounds
- Children in out of home care
- Aboriginal children, especially those in out of home care
- Families from low socio economic backgrounds
- Parents who themselves have mental health issues or other disabilities

As providers since 2007, we have served our community under a recurrent Government funding model (Department of Aging, Disability and Home Care – ADHC), through the Helping Children with Autism (HCWA) funding and now under the National Disability Insurance Scheme (NDIS). We also have experience as parents of children trying to navigate these schemes. From these two perspectives we have identified multiple issues and are offering what we consider to be basic recommendations for overcoming these issues. Many of the issues below are from a previous discussion paper written with my colleague Myrna Dominguez, however I have included them for your perusal as most are relevant for the purpose of this inquiry.

There will never be a way to effectively meet the needs of every person with the one scheme. We propose a number of funded schemes that families can choose to enter depending on the complexity of the disability. We believe our recommendations are simple, cost effective solutions that will see the sector remain viable and sustainable while offering holistic intervention, supports and services to those in need.

Grace Fava OAM

Founder/CEO

Sector	Issue	Recommendations
Assessments	Many parents cannot afford a Paediatrician for an assessment for their child. Community Health in South West Sydney have waiting lists of 18-24 months. For those with significant and complex needs that are apparent early, these wait times put their development at risk of further regression instead of improvement through early intervention.	✓ Better Medicare subsidies for assessments. ✓ **Increase funding for Developmental Pediatricians in Community Pediatrics.**
Assessments	Assessments performed by Psychologists (must be completed by a Clinical Psychologist) will not be accepted by the NDIA unless co signed by an Occupational Therapist or a Pediatrician. This puts a financial and time burden of the family and the child.	✓ **Change the criteria from Clinical Psychologist to Psychologist with 5 years experience for accepted diagnoses when an accredited diagnostic assessment tool is used.**
Workforce	There is a great shortage across most areas of the disability sector for staff including Doctors, developmental pediatricians, allied health staff, nurses, teachers and early years educators especially any with special needs training and education. The allied health shortage is attributed to the lack of paid supervision for students in their final year of study.	✓ **Government to organize a major recruitment drive for high school students over a number of years to highlight the benefits of working within this sector.** ✓ **Government to work with TAFE / Universities around workforce planning and training.** ✓ **Government/Universities to pay external supervisor roles.** ✓ **Government to invest in incentives to address skills shortages in the disability sector.**
Workforce	There is no easy way to provide an NDIS type of scheme for early intervention. No organization can manage to provide intervention to the amount of children in need. This amount increases exponentially each year, not due to better understanding and diagnostics, but due to the	✓ **Change the NDIS for early intervention back to a similar system as HCWA.** ✓ Each child receives an amount of funding under a Medicare type arrangement that they can use with registered providers.

	increase in children with a diagnosis.	✓ These providers are listed on a website that parents can easily access. ✓ I recommend 60 hours of therapy per year per child. ✓ Provider travel can take up a large portion of this funding, there should be a guide of what they can claim to maximise therapy supports. ✓ **If a child requires any more than this due to their complex needs, then they can apply to the NDIS for a fuller plan.**
NDIS	The NDIS is pushing back on Psychology to have it funded under the public system or as an out of pocket fee. Public Psychology services in South West Sydney state they are not an ongoing concern. The staff are not experienced in specific disabilities and there are not enough staff to take on the people requiring services.	✓ **Fund psychology under NDIS where it is disability related.** ✓ Recruit more workers in the workforce ✓ **Increase the amount of public mental health clinics that bulk bill in line with population growth and need.**
NDIS	Psychologists charge at the NDIS rate of $222.14 per hour. This is out of reach of most families.	✓ **Increase the amount of public mental health clinics that bulk bill in line with population growth and need.** ✓ Offer incentives for bulk billing patients with no gap fee.
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 NDIS QSC 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. ✓ Therapists to work a minimum of 5 years for a large organization or sole practitioner before being allowed to work for themselves to ensure that participants are getting quality and best practice supports.
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	Too many plans have funding slashed without cause. On rejection of a review, they are sent to the ART, 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 ART 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.
NDIS **DCJ** **Health**	NDIA say it is not reasonable and necessary for children with limited informal supports to have core support funding for parents who require hospitalization and time to recover. Planners and LAC's say it is parental responsibility to care for children. This is not possible when you have a single parent family or parents are at breaking point.	✓ Have NDIS planners and ART solicitors become familiar with the changes in the ACT where a holistic approach is taken. ✓ **Value for money is supporting families today and not allowing them to face crisis point or relinquish care. This will cost many times more in funding.**
DCJ	When a family moves regions, there is no follow up between the regions to ensure continuity of care. It is rare to see DJC workers commit to supporting families in crisis.	✓ Ongoing communication and collaboration between regional staff. ✓ Clear direction from DCJ on where families can go for support when they say they cannot assist. ✓ **Families with complex needs to go in front of a multidisciplinary panel that includes NDIS, education, police, health and mental health so cases are not prematurely closed.**
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	✓ **NDIS to fund Psychiatrists when the issue is related to a participants disability.** ✓ **More developmental Pediatricians and Psychiatrists who understand complex disorders to be offered incentives to bulk bill both in private practice and in the health system.**

	their case if they are on medication.	
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/Pediatricians 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 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.	✓ Training for all staff on mental health/intellectual disability and Autism across all sectors ✓ **Better staffing in hospitals to avoid "tick and flick" attitude.** ✓ 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. ✓ For a hospital Liaison Officer to check in with the family post discharge.
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 expedite 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 of the previous 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. Sadly students require evidence on their need for a special placement which means they are suspended and placed on partial enrolments. Presently the Principal has the final say on placement of units in their school. In many cases, 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. ✓ **Suspension and partial enrolment is not the answer. If there were more early intervention classes, schools can be prewarned to the needs of the student, leading to a more successful outcome.** ✓ 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	For many families school is the only setting where interventions can take place. Some schools are now charging therapists to enter the school. This is draining an already underfunded NDIS plan especially when travel is charged, leading to less therapy time for the participant.	✓ Each school is to choose registered service providers to service the students in the school.
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.
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 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 incentive for developers to build appropriate social housing for this cohort of people.** ✓ An easier process for NDIS and non NDIS participants to access timely and affordable homes, especially in times of crisis. ✓ A safety net scheme for people with disabilities who are at risk of homelessness. ✓ **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.
NDIS	Providers billing maximum rate for provider travel. Some providers charging for 60 mins therapy, 30 min travel to client, 30 min return to office. This causes funds to deplete at double the funded rate. NDIS state they do not fund for provider travel, but, they allow it in their pricing guide. Providers can charge 60 mins travel per client, plus kms.	✓ NDIS to enforce rules around provider travel. Perhaps incorporating a flat fee for travel. ✓ If NDIS do not fund provider travel, then it shouldn't be stated in the price guide. Reconsider wording in guide. ✓ Maybe change pricing for clinic based vs mobile. Different rates for the different service which would eliminate the travel fees.

DCJ	Families in crisis can only access support by contacting DCJ. This presents them with a conundrum as the thought of reaching out to this government department conjures thoughts of having their children taken away and being judged as bad parents. There are programs that DCJ refer to however these are generalized support services and you can only access them through DCJ.	✓ Fund a direct line of "safety net" providers outside of DCJ that families can reach out to directly for support where there is no direct risk to the child. ✓ This will be a range of providers to ensure families can be supported in a way that meets their families needs and not one provider who uses a "one size fits all" approach. EG Autism, Cerebral Palsy, physical disabilities, invisible disabilities, CALD and indigenous.