Cri Du Chat Support Group Ltd

Information. Friendship. Support.

Consultation response: NDIS Supports Rules (Support lists)

Context

The purpose of this document is to provide feedback regarding the NDIS Supports rules (Support lists), introduced in October 2024. The feedback has been collected using a variety of methods from members of the Cri du Chat Support Group Ltd (Australia) [The Support Group]. The Support Group aims to represent and advocate for parents/carers and families of persons with Cri du Chat Syndrome and persons with Cri du Chat Syndrome.

Cri du Chat Syndrome is caused by a deletion on the fifth chromosome. It is a relatively rare genetic condition with an estimated incidence of between around 1:25000 to 1:50000 births. The deletion results in a cluster of characteristics, including: intellectual disability, global low muscle tone and communication difficulties. People with Cri du Chat have a life long disability, many with an intellectual disability in the severe range, complex sensory issues, global low muscle tone, communication difficulties, and a significant number being non-verbal. For more detailed information please see the website https://criduchat.org.au/professional/.

To our knowledge, all people with Cri du Chat Syndrome in Australia access the NDIS to assist them to live their day to day lives. We are not aware of any people with Cri du Chat syndrome in Australia living independently. As a result, the NDIS and related issues have a direct impact on the lives of people with Cri du Chat syndrome and their families.

The information collated in this document has been provided to the Down Syndrome Australia DRO Consortium, of which the Support Group is a member. The Consortium is free to draw on the information as it sees fit in the development of the Consortium submission regarding Support Lists.

Background

Many members report information, planning and advocacy fatigue. Exhausted by the process of fighting for, managing and implementing complex plans as well as feeling under siege. Many members have elected to remove themselves from groups like NDIS Grassroots on social media due to the stress induced. As a result many are not aware of NDIS news as it arises. Many members were not immediately aware of the 3rd October changes and the introduction of support lists. DRO representatives are aware of this lack of awareness up until late 2024.

Families now absorb the burden of advocating for funding, managing plans, sourcing supports, filling shifts due to absenteeism, invoicing and providing support during non funded periods of the day. Pre-NDIS, these tasks were undertaken by government departments. There is no doubt that choice and control and market flexibility has delivered huge improvements but the burden of administration has been absorbed by unpaid carers.

Support Lists

The majority of our members do not believe 'In' and 'Out' lists work given everyone's different needs. The lists are too restrictive and prevent flexibility in using funding creatively to achieve goals in a cost effective way. Our members report confusion over what they can spend their NDIS core budget on since the introduction of the support lists.

None believe the support lists have increased clarity in what they can use NDIS funds for, rather the lists have caused confusion and have been used by planners and LACs in a punitive manner.

- Quote from member: *"Overall, our experience at review appeared that from the NDIS planners perspective, as much as could be denied, should be denied, whilst using the No list as a tool to support the refusal, even if it didn't apply, and the only response to challenges was 'You can appeal if you don't agree'".*
- Planner advised a family that there are contradictions in the two lists, and that where there is a contradiction the No list overrides the Yes list:
    - The Yes list states the NDIS will fund transport to school where it is proven the participant cannot use public transport independently, however the No list speaks of parental responsibility, so transport to school is refused.
    - The Yes list states the NDIS will fund assistance to manage life transitions. In this family's case, the transition from primary to high school. However, the No list says NDIS does not fund education, therefore the planner would not include any additional funding to support transition. The result for this family has been significant mental health challenges for the participant, who was largely unsupported in a major life transition due to an inability to train the school in their needs due to NDIS funding decisions.

Many items are fraught with lack of clarity causing confusion both for participants and their families as well as planners.

- On the No list: Transport for children as part of their reasonable care and support provided by families or carers. This is being used against families for all support worker transport, some which is beyond typical parental responsibility and does not consider the stress placed on families with multiple children balancing therapy appointments and other daily life and work commitments.

Planning Experience

Only a few members have reported having had a plan re-assessment since 3rd October 2024. Of those that have, all have reported funding cuts attributed to the support lists. Many members have reported having a LAC, Support Coordinator, or someone from the NDIS tell them they can't use their NDIS plan for an activity or support they previously used it for.

One member had their consumables funding reduced from over $20,000 in the plan prior to the introduction of Support Lists, to $8000 after the introduction of the Support Lists. The participant's support needs had increased across this period.

Vague statements such as 'reasonable care and support provided by families' are being weaponised by planners against families. We have received multiple reports of families with an adult child with a different diagnosis (which also require life-long care) being told supporting adult children who have left school during weekdays is "parental responsibility". This is a significant development and detrimental to the long term sustainability of the scheme where people have the option of living in the family home as an adult. Families will be forced to relinquish care of their adult children in order to access suitable support, resulting in the person with a disability requiring 24 hour SIL funding. We hold concerns that this could also happen to members within our Cri du Chat community, and the fact this is happening to others is causing anxiety for our members.

The planning experience has become a very stressful, time-pressured experience with families having no control over timing. Some reviews are happening over the phone with no prior warning, families are not always understanding that the phone call is a Planning meeting, others have requested a review and have had to wait 12 months. One family describes how reports were requested in January 2024 to support a review, however, the plan review did not occur until January 2025. Reports pre-dated the 3rd October changes and were therefore irrelevant and not tailored to the current NDIS environment. This resulted in an unfavourable outcome for the family, where items sought in reports no longer aligned with the newly introduced Support Lists.

Families with adult participants in SIL accommodation report long term funding being reduced, even though there has been no improvement in functional capacity - intellectual disability due to chromosomal abnormality is a life long disability. The NDIA has requested additional assessments and reports in addition to the reports provided at review. The funding allocated in this example is not enough for the current placement to be financially viable and provide safe supports that meet NDIS Commission and community standards.

Lifestyle related

Lifestyle related expenses should be considered in the context of the majority of our members being on the Disability Support Pension. These items may be 'everyday items' for some, however for our community they are disability related/disability specific items and should be included on the 'Yes' List:

- Tablets, robust protective cases, accessories (mounts and key guards) and applications used to support Assistive and Alternative Communication [tablets used for entertainment purposes should remain family funded]
- Many people with Cri du Chat syndrome do not have safety awareness and wander. GPS tracking smart watches are a disability specific need for our members.

- Music and art therapy are approved therapies, however many people are being denied funding when they request these be included in their plans. Clarification over what is an ‘evidence-based’ support.
- Specialist or private swimming or water safety lessons should be funded for children who are unable to participate in mainstream lessons due to specialist instructors, equipment, access or sensory limitations should be funded and the funding should extend throughout adulthood. “Drowning is the leading cause of death among children with Autism Spectrum Disorder (ASD) (University of the Sciences in Philadelphia, 2014).” [https://www.autismawareness.com.au/aupdate/drowning-and-asd]. In addition to the safety issue, swimming is one of the few types of exercise available to people with physical disabilities, including those who are unable to bear weight.
- Gym memberships - all of our members require physiotherapy. Being able to do this in a community setting (gym) is a cost effective, motivating and inclusive way to complete physiotherapy.
- Standard indoor and outdoor play equipment: this rules out purchasing items for a home physiotherapy program, prescribed by a person’s therapist for daily therapy in the participant’s natural environment.

Disability Related Conferences and Camps

Parenting a child with a rare chromosomal syndrome is a daunting experience, well outside of the expectations and experience of parenting a neurotypical child. This responsibility does not end with adulthood being attained. Parents are required to learn not only about the Syndrome but become experts in very specific subject areas:

- Medical complexities
- Early Intervention
- Complex and non-verbal communication needs
- Complex behaviours, including self-harm and aggressive behaviours
- Complex Sensory requirements

Parenting a child with these complexities is exhausting, isolating and ongoing. Parents are on a journey, many with no prior disability knowledge or experience. Conferences offer a cost effective way for parents to access information, keep up to date with current issues in disability (restrictive practices, active support) and build peer-to-peer networks. For example, people with Cri du Chat syndrome have complex communication needs and AGOSCI (Australia's Group Supporting Communication Inclusion) has proven to be a valuable conference for many of our families.

These conferences are expensive and out of reach for our families to self-fund. When our families cannot attend these conferences, their capacity to best support their child is compromised. Members report having had booked to attend disability related conferences prior to the Support Lists being introduced, however the conferences were held after 3 October 2024 and they were therefore unable to claim the conference expenses. This was unfair on families and jeopardised their personal finances.

The Cri du Chat Support Group is holding our bi-annual National family conference in October 2025. The Family Centred Conference provides a connection and upskilling

opportunity for parents, and well as social connection opportunities for people living with Cri du Chat syndrome and their siblings.

Some members advise that having conferences on the ‘No’ list is directly affecting their decision to attend the conference. Many interstate members advise that their decision to bring or not bring a support worker to the conference is directly related to being unable to claim the support worker airfare and accommodation expenses using their NDIS funding.

Support for Conference attendance is a significant issue for the geographically disperse Cri du Chat Community:-

- People with Cri du Chat syndrome have complex support needs (communication, behaviour, physical, sensory) requiring personalised, trained 1:1 support worker assistance, which means families cannot engage an interstate support worker to assist them as a once off at a conference or other trip. To have support, they must take their regular, trained support worker with them.
- Many of our families have one parent who works reduced hours due to the support needs of their family member with Cri du Chat syndrome. This affects their financial capacity to pay an additional $1500-$2000 to fly and accommodate a support worker at our conference. None of our members with Cri du Chat syndrome work full time to be in a position to financially cover this expense, the vast majority are on the DSP.
- These two factors combined mean many people with Cri du Chat syndrome and their families miss out on valuable experiences, be they interstate trips or attendance at disability specific conferences where invaluable knowledge and connections are made. This disadvantage is as a direct result of the person’s disability and subsequent support needs.

A support worker is a support required as a direct result of the person’s disability, and as such is funded by the NDIS. The expenses incurred in travelling with a support worker to a disability specific conference are as a direct result of the person’s disability. The Cri du Chat Support Group of Australia Ltd believes support worker airfares and accommodation should be claimable under a person’s NDIS plan where the person has complex needs requiring a known support worker to travel with them. This extends beyond conferences to any reasonable travel undertaken by the person with disability.

We submit support worker travel and accommodation should be included on the ‘Yes’ list for a class of participants, as is allowed under Section 10 of the amended NDIS Act. We submit this class of participants should be those identified as those with complex high-risk behavioural, communication, and other needs requiring trained 1:1 supports.

- Excluding funding for travel/accommodation expenses for support workers would deny this group equitable access to activities available to others with less complex needs.
- This contradicts the principle that NDIS supports should enable equal opportunity for community participation, regardless of disability severity.

Employing a new support worker at the destination is:

- Unsafe (risk of injury, behavioural escalation);
- Ineffective (support outcomes cannot be achieved);

- Wasteful (NDIS would be funding supports that don't work).

Funding a familiar worker's travel and accommodation is reasonable and necessary to deliver the support itself.

Requiring a participant to access support only with a new/available worker at the destination:

- Penalises them for their level of disability;
- Limits their ability to travel for recreation, medical reasons, family events, conferences, or therapy intensives;
- Breaches NDIS principles of choice, control, and inclusion.

This would amount to discriminatory exclusion, especially when the only barrier to participation is the refusal to fund enabling costs like worker travel.

Funding the travel and accommodation of a participant's known support worker is:

- Reasonable and necessary for safe, effective support delivery;
- Aligned with the NDIS Act 2024 amendments, which allow tailored supports for defined participant groups;
- Essential for upholding participants rights to inclusion, autonomy, and dignity;
- A more cost-effective and evidence-informed approach than attempting to engage unfamiliar workers for high-risk individuals.

This support should therefore be included on the "Yes list" for participants with clearly documented, complex 1:1 support needs. We submit this is the majority of people with Cri du Chat syndrome accessing the NDIS. If included as a class of participants eligible for this support, the NDIS should not increase the threshold to be identified as a participant with high-support needs simply to reduce the number of participants eligible for this support item.

In a similar vein, disability specific camps are another way of providing support to people with a disability and their families. Intensive "therapy" camps can provide a socially acceptable way of packaging "therapy" to young people during school holidays. Likewise, "respite" camps during school holidays can provide families with a break and the person with a disability the opportunity to develop confidence in spending time away from the family. One of our families report having Disability specific camps refused [one therapy and one respite] due to the use of 'camp' in their title. The Planner was not interested in taking the time to understand the type of camp, just saying No at the sight of the word "camp" as this is on the 'No' List, advising the family they could request a review of the decision. However, the annual therapy camp was to be 4 weeks after the Planning meeting and a review would not be able to be completed in time. The child was unable to attend. The use of a word in a quote should not be used to refuse funding simply because that word is included on the No list, without understanding what the quote is actually for.

Insurance

House and contents insurance is on the No List. Whilst we agree this is appropriate, we do believe additional insurance premiums due to insuring disability specific items should be included on the Yes List.

- Car insurance: Disability specific car seats (e.g. Carrot 3000): mainstream car insurance companies are unable to add additional cover beyond the few hundred dollars for a typical car seat. A Carrot car seat costs $8000. Blue Badge Insurance is the only insurance company that covers such an expensive car seat, with the additional cost to families on the insurance premium being around $200. This additional component is a disability specific expense and should be funded in a participants' NDIS plan.

- Wheelchairs: Many people insure their wheelchair. They can be worth more than their car. This is a direct disability related expense.
- Speech generating devices: These are worth thousands of dollars and are carried with a person everywhere. They may leave it on the table at a restaurant and go to the bathroom. Many insure them for peace of mind and to ensure a quick replacement should the item be lost or stolen. This additional disability related expense costs families upwards of an additional $400 on their insurance premium annually. We submit this should be included on the 'Yes' List.

Items being on the No List when under certain circumstances they could be a disability specific item

We see some items on the No list that in certain circumstances could be items that should reasonably be funded by the NDIS. By being on the No list, it removes flexible and creative thinking. For example, e-scooters could be a great option for people with low tone to participate in their community. Similarly, e-bikes with passenger functionality is another great mainstream option for families with a child or young person who is unable to ride a bike to be able to participate in a mainstream activity with appropriate support. It is likely this would be a cheaper option than a specialised disability passenger bike.

Similarly, what is a typical household item for some is a disability related expense for others. For the majority of our families, their child with Cri du Chat syndrome has complex communication needs and requires visual aides to support their communication. It is more time and cost effective for the NDIS for families to make these supports themselves, rather than pay the hourly therapy rate for these visuals to be made by an allied health professional. For our families, a printer, ink, laminator, velcro, and hole punch are disability related expenses.

Tablets are on the No list, however again these are a specific communication tool for our families. Whilst NDIS will fund one speech generating device, the current Support Lists do not allow flexibility for funding for an iPad to be included as a modelling device for the communication partner. This is a critical gap for our families, and being told by NDIS employees that 'everyone owns an iPad so it's not an NDIS funded support' shows a lack of understanding of complex communication needs. Our families fund their own personal iPad's, however this is an additional device purely for communication support. This is a problem facing many of our families and we submit modelling device iPads should be included on the 'Yes' List.

Replacement Supports

None of our members report having used or asked about the replacement process. The process appears to be a complicated, bureaucratic, time consuming and expensive (to Government) process, to have a simpler, more cost-effective, more efficient support funded. It appears it will cost the government more money rather than save money due to the therapist reports required. It will only save the government money if participants are deterred by the complex process and don't pursue it at all.

Relevance to ALL members

We note the contents of this document relate to <u>all</u> of our members, regardless of age or personal living arrangements (living at home or away from home in supported accommodation).

Summary

The Cri du Chat Support Group of Australia Ltd has seen its members experience challenges and confusion as a result of the introduction of the NDIS Support Lists.

Since the introduction of the "In" and "Out" support lists under the 2024 amendments to the NDIS Act, all of our members who have undergone a plan reassessment have experienced a reduction in funding. These reductions are directly attributable to the implementation of the new Support Lists.

Most members report that they are now unsure how their Core funding can be used—beyond paying for a support worker and purchasing continence products. This represents a significant loss of the flexibility that previously allowed families to respond creatively and individually to their child's or loved one's needs.

The majority of our members have significant, high-level care requirements, and the current restrictive framework does not reflect the diversity or complexity of the supports they require. Many of the excluded supports previously made a meaningful difference in quality of life, skill development, safety, and inclusion.

We submit that the Support Lists are not responsive to the needs of participants with complex disabilities including Cri du Chat syndrome, and that the former principles-based approach, which considered what was reasonable and necessary on an individual basis, provided significantly better outcomes for our community.

If a principles-based approach is no longer considered viable under the amended legislation, we urge the NDIS to make full use of the provision in Section 10(1) of the Act which allows for supports to be declared as "in" for specific classes of participants. Participants with complex support needs should be recognised as such a class, with a broader and more flexible list of allowable supports tailored to their needs.

Furthermore, given the difficulties experienced by families during plan reassessment since the introduction of the Support Lists, we strongly encourage the NDIA to ensure appropriate staff training on the application of the new lists prior to any further plan re-assessments. This should include:

- A longer transition period before full implementation;
- Direction for staff to apply nuanced understanding of quotes and support contexts, rather than making decisions based on keywords that may appear on the "No List" without considering the function, outcome, or rationale behind the requested support.

Without this, participants with complex needs will continue to be disadvantaged by an approach that prioritises administrative simplicity over genuine understanding of individual requirements.

Cri du Chat Support Group of Australia Ltd
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