Complex Care Group Submission to the Ministry of Social Development Disability Support Services Taskforce on Recommendations Five and Six of the Independent Review into Disability Support Services

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Introduction

Complex Care Group (CCG) is a Disability Information Advisory Service (DIAS) who provide information and support to families and carers of children, young people and adults, who have either multiple disabilities, a serious, ongoing medical condition and/or behaviour that requires a high level of support. To find out more about how/why CCG was established please read here: https://www.complexcaregroup.org.nz/about/about-complex-care-group/

Our membership is made up of families who have a child, young person or adult with a disability that requires **intensive support**:

- Because the person has multiple disabilities, e.g. is physically disabled and has an intellectual disability
- Is disabled and has a serious ongoing medical condition
- Is disabled and has autism spectrum disorder or behaviour that requires a high level of support

The group began supporting families with children that required intensive support, but as original family members and their children have aged the group has adapted to include the families still caring for their complex disabled adult children. Some of these members have children now in their 40s and 50s.

We currently have over 400 members, however, in 2023, there were 4,179 people receiving Disability Support Services (DSS) packages between $105,000 to $333,000 and 158 over $333,000 (Shaw, 2024). This is just under 9% of those receiving disability supports who would now require panel review based on the new NASC policy guidelines.

There has been significant growth in the Very High Needs category for DSS from 2013 to 2023. In Meeting the Need (NZEIR, 2024) it is acknowledged that the complexity of disability has increased – in 2013, there were 7371 disabled people categorised as VHN and by 2023, there were 13,518. Over this 10-year period, data shows that in 2013, the most common category of SPA level was medium followed by high. In 2023, the most common category was High, followed by Very High.

The data is showing that complex disability is on the increase and this needs to be acknowledged in policy and funding packages in the future for both the disabled person and their family.

Background

Existing Supports

Under current needs assessment guidelines for disability, most of our members receive Disability Supports and would be assessed as having Very High Needs using the Support Package Allocation (SPA) tool via their Disability NASCs. There are some who are assessed as High Needs but may still have a complex disability due to co-morbidities which may not fit a disability diagnosis, e.g. FASD or are funded primarily via another government ministry or agency.

For example, a member may have primary or additional support funding through any of the following:

- Health NASC – Long Term Supports Chronic Health Conditions (LTS-CHC)
- Mental Health NASC
- Accident Compensation Corporation (ACC)

The disabled person and family may also receive temporary/fixed period additional support from the following:

- Intensive Wraparound Service (IWS)
- High and Complex Needs Unit (HCN) – Intersectoral Strategy
- Strengthening Families

These temporary/fixed term supports are offered when needs are not being met by the existing frameworks and sit within a variety of government budgets, often as collaborations across agencies. The fact that these exist, suggests that there are complex disabled people and families who have unmet needs within the existing frameworks.

To understand the complexity that a family may be dealing with it is important to understand the other types of support that they may source from other government ministries and agencies depending on each person's unique complexity and need. Like Disability, there are transitions at 5 years old and when leaving school and becoming an adult.

Within education (5 years to 18-21), our members generally receive either Very High Needs ORS support or High Needs ORS from the Ministry of Education. Some members may be alternatively funded via the High Health Needs support from Ministry of Health. Due to

inadequacies in the mainstream (and Special Education) system in New Zealand, some parents of complexly disabled children choose to homeschool their child or educate them via Te Aho o Te Kura Pounamu (‘correspondence school’).

After school has finished those with VHN funding transfer from MOE to the Ministry of Social Development (MSD) and receive a VHN package, which provides a one size fits all annual amount, that supports around 15 hours support on a 1:3 or 1:4 basis in a day programme or an annual amount of just over $20,000 per person. Those with High Needs ORS receive limited support via MSD under bulk funded community participation funding if they wish to use a day program. Within VHN funding during school years, those attending ‘special schools’ will have relatively good access to allied health services, ie. Speech Language Therapy, Physiotherapy and Occupational Therapists. Some schools will also provide a psychologist. If a high and complex needs person attends a mainstream school, or is homeschooled, these supports are often less easy to access due to waitlists.

Within the health system, a child with a serious ongoing medical condition will also be under the Child Development service up until school age and may receive speech language therapy, physiotherapy, occupational therapy and other early intervention services. They may also be using a Dietician or other specialist interventions according to their diagnosis.

In terms of disability support funding, the current maximum allocations per child/adult for VHN, as described in the 2016 Support Package Allocation Tool are:

Age range	Weekly Maximum allocation	Annual allocation
0-5 years	$250	$13,000
5 years to school leaver	$900	$46,800
School leaver to adult (U 65)	$1500	$78,000

The ‘needs assessment’ has traditionally focused on functionality of a person, and their deficits using the medical model to analyse the need for ‘tasks’ performed by a support worker for personal cares and for household management. More recently, the needs assessments have been moved towards using the social model of disability and disabled people and their families may have been asked to complete an outcome plan. The information gathered in the needs assessment is then measured against the SPA tool. We agree with the findings of the Independent Review, Paragraph 124, that it is difficult to see how the current tools needs and pricing set in 2016 dollars, translates into the funded package of supports that a client needs and/or receives.

The numbers provided in the SPA tool for maximum support for someone with VHN are shown as $78,000 pa (school leaver to adult), yet we know that we have a multitude of people receiving over $105,000 pa. It is widely recognised that with pay equity, inflation and other factors, the SPA tool is incredibly out of date.

It is also unclear whether the SPA tool has a quantitative measurement for calculation of respite and family wellbeing.

Understanding the impacts of Complex Disability on family carers

Many people with the complex level of need we support and advocate for may be unable to advocate for themselves e.g. have limited communication, are non-verbal or have an Intellectual Disability that affects their capacity to make decisions. They therefore become reliant on their family to fill this role for them. It is widely accepted that Family Caregivers often serve as the Primary Care co-ordinators for their children (Reinhard & Levine, 2012). As New Zealand's current system is incredibly fragmented, siloed and difficult to navigate, this means that the person needing support will often only receive support based on the capacity and capability of the parent/family advocating and caring for them. This is not a fair system.

There are numerous pieces of research that show that parent(s)/families, whanau caring for those with complex needs are more likely to suffer from caregiver burnout, depression and isolation. This is particularly true when there is a combination of medical technology dependence (ventilation, intravenous nutrition/medication, respiratory/nutritional support) which may fall under 'health needs'. Mothers of technology-dependent children are at high risk for clinical depression that may affect family functioning (Boebel Toly, Musil & Carl, 2010).

Families who are caring for those with complex needs are also more likely to ~~have~~ need to move their child/adult into residential care. When family wellbeing is not sustained through adequate supports and/or respite or the family is no longer able to do the care, the progression is usually into residential care due to the need for 24/7 care and supervision. Currently, due to a significant shortfall in residential care options for those with complex disability (especially those with a combination of medical and disability needs) there are over 850 young people (aged under 65) in aged residential care as there are no other safe alternatives.

Complex carers make a significant economic sacrifice due to caregiving responsibilities. In the 2022 report - The Economic Contribution and Sacrifices of Unpaid Family, Whanau and Aiga Carers in New Zealand, it is shown that carers have lower household incomes, carers incomes are affected by their working hours and more are in part time work than the general population (Infometrics, 2022). Complex carers are often reduced to poverty.

Complex Care Group completed the Voices Project Report in March 2020, and in terms of Needs Assessment and Service Coordination the most consistent concerns reflected in the Voices project were around:

1. Eligibility criteria – disabled people with demonstrated need but not quite "fitting the box".

2. Concern that the disabled person is not getting sufficient support from NASC due to lack of understanding about very high and complex disability needs (and thus onus on parents to exhaustively explain the needs in a way the NASC assessor will understand, fitted within the common assessment domains of a NASC).

The full Voices Project Report is included as Attachment A.

Many of the issues facing the complex disabled and their carers have been widely reported on over the last 20 years, yet there has been little focus on this unique group in service and policy provision during this time. The restrictions placed on disability support services on 18 March 2024, the new NASC Operational Policy guidelines and the restrictions placed on entry into residential care have severely impacted our community.

The Honorable Minister Louise Upston has repeatedly commented that those with the 'highest needs' will be supported. If we were to assume that the highest needs are those with the most intensive support needs, this would indicate that disabled people who meet our definition of complex disability would be adequately supported. However, both 'highest needs' and 'complex disability' have a variety of meanings depending on context. We will discuss the need for clearer definitions in our recommendations section.

In New Zealand, it remains unclear who is considered to have the highest needs and how many disabled people and families would be in this category due to the inadequate capture and use of data across the varying government agencies. Recent Australian research on workforce planning (Dowse et al, 2016) imputed that 11.9% of the Australian Disability Market had either intellectual disability or complex needs. If we were to extrapolate that percentage to the New Zealand market, we could expect that of our 50,000 receiving DSS,

that there might be up to 6000 people with either Intellectual Disability and/or complex disability. We include Intellectual disability in this category as once a person with ID has become an adult, it is most likely that they will need 24/7 care or supervision. This is a big difference to our membership of approximately 400 and flags a **significant workforce development issue** for long term complex care. Complex Care Group acknowledges the challenges of reaching families we know are out there – accessing them depends on regular promotion of our service to medical professionals and other disability paraprofessionals.

Recommendation 5 from the Independent Review of Disability Support Services is to:

- Update the assessment and allocation settings for individuals based on level of need.

The subsequent August Cabinet Paper, Paragraph 17 states as follows:

"In considering next steps for the recommendations, I want to emphasise that:

> 17.1 disabled people **deserve certain and consistent DSS, no matter where they live**
>
> 17.2 prioritising funding for those **with the highest needs**, and who would benefit most from early intervention, is consistent with our social investment approach
>
> 17.3 **the Government is committed to the EGL vision and principles**
>
> 17.4 it is important to strengthen the long-term sustainability of DSS to provide **disabled people and carers** with services that are both fair and affordable."

Under the existing SPA, the 5 funding categories range from Very Low to Very High. Using the current assessment method, those with complex (needs) disability should be assessed as Very High Needs as they require intensive support, and the impacts are very significant. This would be applicable for the three stages of birth to 5 years, 5 years to school leavers and school leavers and adults used in the SPA tool. The existing assessment and allocation settings do not currently meet the needs of those with complex disability and their families.

Discussion

For those with complex disability and their families, the SPA tool does not adequately capture the needs of the disabled person and their family - and supports do not adequately address the need for 24/7 care, supervision and complex support tasks. Also, many family carers are unable to hold down a fulltime job around caring responsibilities and have poorer health and mental health outcomes due to insufficient supports and respite.

The existing Disability Support Package Allocation (SPA) tool does not adequately assess and support disabled persons and families who present with complex disability that require intensive support as per our definition. We have identified problems with the assessment and allocation process as follows:

1. The Very High Needs, Highest Needs and High and Complex needs definitions are inconsistent across government agencies – disability, health, education, social development and mental health.

   We have been unable to identify the total number of persons who would be considered ‘complex’ under Whaikaha, the Ministry of Health, and the Ministry of Education due to a lack of available and specific data that identifies people that have complex needs supported across different government budgets. This is further complicated as different Government Ministries and agencies have a variety of definitions for what is considered complex care.

   Refer to Attachment B for a sample of definitions in use.

2. The disability needs assessment is based on task-oriented measurements, e.g. time taken for personal cares, such as bathing, toileting etc and household management, time taken for extra laundry, groceries etc. **The needs assessment does not consider supervision time for young adults over 14 years of age or adults, who would otherwise be able to be left unsupervised if there was no intellectual or complex disability.**

   Supervision time is often required because of risk management due to self-harm, harm to others, safety and vulnerability from Intellectual disability or communication difficulties but this is not seen as a need. Family carers cannot access their human rights on how to live, work, travel etc because they have a ‘duty of care’ responsibility

which is not aging out when the complex disabled person becomes an adult (as it typically would for a family with a non-disabled adult child).

3. Availability of 'natural support' and 'informal support' is used to calculate a reduction in paid support hours. While this works for some families and may be preferred by some cultural groups, for those with complex needs sometimes natural or informal support is not appropriate and even dangerous, **as the tasks or care may be above the level of competence for family members e.g. medical cares, behaviour management.** We would also like to stipulate that many families use 'natural' supports first, early in their child's life – such as asking a grandparent or aunt/uncle of the disabled child to provide some support. This is very common and often preferred prior to accessing funded formal supports. Ultimately, we find that as the complex disabled child becomes older and physical cares become more demanding, and/or behaviour becomes more challenging, families turn to funded formal supports.

   In a US paper, Home Alone: Family Caregivers Providing Complex Chronic Care (Reinhard & Levine, 2012), almost half of family caregivers reported performing medical/nursing tasks with chronic and cognitive conditions. This included preparing food for special diets, using monitors, operating specialised medical equipment, wound care and multiple medications. The report demonstrated that family carers are being asked to perform complex tasks because of economic pressures to reduce hospital stays, the growth of in home technology and because formal home care services may be short term or limited.

4. The SPA tool is used to calculate the number of hours of personal care tasks required, and the designated hourly rate for funding for families using IF is $37 gross per hour, regardless of the complexity of the cares being delivered. This hourly rate is based on the $28.25 net per hour rate of a Level 4 Support Worker. Level 4 Support workers do not receive training on and are not necessarily qualified to deliver more complex tasks, such as those that complex disabled may present with, e.g. inserting an Naso-Gastric Tube, Suctioning, Wound Care, operating medical technology and more.

   It is not only medical care that has complexity. Many with high and complex needs have behavioural/mental health associated conditions which can mean a support worker is dealing with aggression and behavioural challenges.

A Carer with a Level 4 qualification is unlikely to have the skills required for complex care, meaning the workforce is not adequate and places extra pressure on families who are often the back up/trainer or 2:1 person on call while the support worker is present.

5. There is no consistent approach to family wellbeing for those supporting their child or adult and no apparent relationship to how respite is calculated. While respite is recognised as an integral part of family wellbeing and continuing support of a disabled family member, to reduce mental health risks and caregiver burden or burnout, the SPA tool does not include the need for respite as a specification for determining level of need.

   If carers have unmet needs, there are higher risks of stress and depression (Jorgensen, D. et al, 2010). Family caregivers have financial difficulties, feel unsupported and many provide 24 hour, 7 day a week care. This New Zealand study also demonstrates siblings to be suffering due to the increased requirements of the care recipients.

6. There is no recognition of the degree of care co-ordination required for those with complex needs. Parents may deal with multiple NASCS, agencies, health professionals and providers. Parents of high and complex needs children or adults spend many hours coordinating care and services for their child and this is not recognised in the needs assessment. Parents managing care of a person with highest needs, may be recruiting and employing several staff and the HR responsibilities that goes with that, managing complex appointments and scheduling and can only be compensated with an annual $300 recognition fee which is the same whether you have a mild or complex disabled person to support. Dickinson (2017) found that in order for Individualised Funding to be effective support services to manage administrative duties was needed. This is particularly true with the large workload associated with complex disability.

7. There is insufficient data on complex disability to make informed policy. Needs assessment focuses on primary disability and this is not looking at the person holistically. From the independent review, we know that only the top 0.2% receive comprehensive/intensive support ($333,000 - $1.2 million) and that 30% have ‘very large’ packages which are between $35,420 and $333,000.

Each government department or agency is working in a silo and budgets for support are divided by government budget rather than as a personalised budget per person, with separate rules for each government department.

8. ORS education categories of HN and VHN from education being used as a determinant for VHN services and allocations for adults. Not having a VHN diagnosis at school does not mean that a person is not 'complex' as an adult and in need of intensive support as an adult. Education categorisation should not be used for lifelong disability support categorisation. This is in part due to the difficulty obtaining either High or Very High Needs ORS funding. Often a disabled child misses out entirely on ORS funding or otherwise is categorised as High Needs when in fact they meet the criteria for Very High Needs. This mismatch in ORS allocations has long term implications not always understood by the family and by educationalists. ORS funding allocations seem to vary (or are 'scaled') year by year based on number of applications and funding available.

9. MSD VHN funding does not meet funding needs for post school hours (25 hours per week). MSD VHN funding for community participation amounts to 15 hours of a day programme or 12 hours of individualised support. This figure is calculated based on 24,000 per annum paid to an IF user at $37 per hour. This means when a complex disabled person who is unlikely to enter the workforce leaves school, there is an increase in responsibility for the family to provide more care. This is reverse to a 'regular' family dynamic where an adult child no longer requires supervision, care or financial support.

10. Given the capped nature of funded disability supports, coupled with the increasing number of referrals for funded disability supports (particularly in the last five years) the SPA allocation tool would either need to continually elevate the bar for eligibility to the various assessment levels – or be inaccurately applied (that is, the funding level allocated is not matched to the level of disability need).

    Realistic budget bids for funded disability supports should be based on real data in order to accurately reflect the need. Whilst this may at times require increasing the DSS budget for funded supports, this would prevent the avoiding or delaying of support provision which invariably results in higher levels of support – either via DSS or other government departments – at a later stage. This would also better align with the EGL Principle of Beginning Early – there is much research to indicate early

and appropriate supports can prevent considerably higher levels of support being required later in life.

For children and adults with complex needs, the current needs assessment process and allocation processes do not recognise the **complexity** of tasks being performed, the **need for constant one on one supervision (**often referred to as hypervigilance), and expected as ‘natural support’ - and the difference in the **need for respite, that often includes access to nursing or behavioural support** outside the scope of natural family or support worker skill level. There is little recognition on the role family plays in the support of the complex person and recent changes have made the family supports even more difficult to access.

Recommendations

Complex Care Group would like the Disability Support Services Taskforce and Whaikaha to consider the following points and recommendations as part of the consultation for Recommendations 5 and 6 of the Independent Review:

Recommendation 1:

Create an additional multi-agency category to use for assessment that goes across government agencies which is called ‘complex needs’ and is higher than the existing category of ‘very high needs’ used in education, by the Support Package Allocation (SPA) tool and by MSD. In addition to the complexity of the disability, the family circumstances should be weighted into the calculation, e.g. single parent, number of other dependents, caring for parents, poverty, cultural needs.

Recommendation 2:

Compensation for supervision time is allocated up to 24/7 care if this is needed for candidates over the age of 16 years. The compensation can go to a support worker or family member if they do not consider this ‘natural support’ or ‘informal care’ for candidates over the age of 16 years. The age of 16 years is suggested due to other legal forms of decision making, adulthood rights coming into effect at this age, rather than the age of 14 years, where a child may be left unsupervised but is still the full legal responsibility of the parent.

Recommendation 3:

The needs assessment should take into consideration the complexity of the tasks being undertaken. Natural and/or informal support may not be appropriate or safe if the tasks require trained professionals. There needs to be an allocation in the funding for specific (not generic) training to meet the client's needs.

Recommendation 4:

Introduce a higher pay rate for behaviour specialist and/or nursing level care for at least the **respite allocations** of support work care hours or a portion of the total support work hours. This would enable those who have intensive support needs to be supported in a way that is within health and safety regulations, instead of being placed at risk with unqualified staff or the family not being able to take a break to sustain their health and wellbeing.

Recommendation 5:

Allow flexibility of purchasing for in and out of home respite services, which permit overnight accommodation costs for either the disabled person or the parents who need a break. Increasing the daily rate for Individualised Funding Respite from $197 per day to cover the actual cost of 8-24 hours of care, e.g. $37 per hour x 24 hours. Facility based respite and provider respite is not available in all areas and options for purchasing or creating suitable respite for complex disabled cannot be purchased using a carer support day or an IF respite day.

Provide free counselling for parents and siblings of those with complex disability throughout the life stages as needed. This would help improve the mental, emotional and spiritual wellbeing of families, providing resilience for them to continue in their caring role. This would also likely reduce further costs in the future related to the wellbeing of family members including such instances as physical/emotional breakdowns, family unit breakups, single parenting under extraordinarily difficult circumstances – and the resulting financial strain from these circumstances, etc.

Recommendation 6:

Allocation of funding should include the cost of administration for the parent or allocate a navigator/care co-ordinator. The family has replaced the 'agency' and IF does not allow for upskilling of the parent without this being taken from the budget for

Personal Cares. Individualised funding gives disabled people the ability to have choice and control, but for families/parents who are managing the IF budget on behalf of a complex/intellectually disabled person, they are providing a service for free to the government that would have otherwise been considered a service that a provider charged for. This is especially pertinent for families managing complex needs where this can be a time consuming job.

Give families a choice of having a personal budget which includes an administration budget, using providers or having a primary care co-ordinator (navigator).

Recommendation 7:

Enable the needs assessment to recognise multiple disability and cross government needs, to capture the whole cost of the persons disability needs across the various life stages.

Look at the data and remove the caps on numbers to match the need. This would require the government to acknowledge that they have been underfunding disability for years. With more comprehensive data analysis (and adequate disability support services budgets) in future, disability support funding will better match the number of disabled people in the community and their changing support needs over their lifetime.

Recommendation 8:

Full multidisciplinary reassessment is made during the Transition out of school period, ages 16-21 years. Assessment includes all areas of government funded support (multi-disciplinary) and is one package such as originally anticipated under EGL principles: health, disability, MSD, mental health. One budget per disabled person for all these various support needs.

Have a multi disciplinary needs assessment, and then the government agencies agree on who is paying for what, but it is combined in one budget to be easy to use for the person and family. Once System Transformation is reinstated, instead of looking at REGIONAL rollouts of EGL, look at starting with those with the highest needs.

Recommendation 9:

Funding is assessed on support worker hours needed and cost of community participation. Bulk funding to day programmes is increased to meet demand.

Recommendation 10:

Cross party policy is required to remove capped funding for those with high and complex needs. This would provide a solid, reliable and future-proofed support system providing for those with the highest support needs.

What are the benefits of resourcing families with complex needs?

1. Parents may be able to return to work full time as their child/adult child is being supported by a qualified support worker.

2. High and complex people are more at risk of entering residential care - and resourcing their care during childhood (beginning early) will help the family be able to sustain their caring role for as long as practicable.

3. The complex disabled person will have more choice about what they can do after they leave school, instead of needing to enter a day programme as that is the only affordable option.

4. Families (parents and siblings) mental health outcomes should improve as there should be less risk of isolation and caregiver burnout as they will be better supported.

5. Long term benefits of improving outcomes for those with complex needs to reduce potential criminal offending and entrance into secure care.

6. Reducing entry of young people into Aged Residential Care. Currently around 850 young people are in aged residential care and 80% of these have high medical needs. This is because there are no alternatives for adult respite or residential care that meets the needs of someone with very complex medical and disability needs.

References:

Boebel Toly, Vl, Musil, C.M., & Carl, J.C. (2010). Families with children who are technology dependent: normalisation and family functioning. *Western Journal of Nursing, 34*(1), 52-71.

Dickinson, H. (2017). Individualised funding systems: What works?. *Evidence Base, Vol. 2017, Issue 3.* DOI: 10.21307/eb-2017-003

Dowse, L., Wiese, M., Dew, A., Smith, L., Collings, S., & Didi, A. (2016). More, better, or different? NDIS workforce planning for people with intellectual disability and complex support needs. *Journal of Intellectual & Developmental Disability*, *41*(1), 81–84. https://doi.org/10.3109/13668250.2015.1125868

Jorgensen, D., Parsons, M., Jacobs, S., & Arksey, H. (2010). The New Zealand informal caregivers and their unmet needs. *The New Zealand Medical Journal, 123* (1317), 9-16.

NZIER. (2024). Meeting the Need: A funding analysis of New Zealand's Needs Assessment and Service Co-ordination providers (NASCS). A report for NASCA.

Reinhard, S.C., Levine, C., & Samis, S. (2012). Home Alone: Family Caregivers Providing Complex Chronic Care. Retrieved from https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

Shaw, A. (2024, November 11). *OIA3516, Letter from Anne Shaw to Cherie Cawdron*. Unpublished letter.