

# Response ID ANON-SUDQ-DKKE-V

Submitted to Highest Needs Review  
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## Introduction

1 Are you submitting as an individual or on behalf of an organisation?

Organisation (please specify below)

Organisation name (if relevant):  
Rare Disorders NZ

2 What is your relationship with the Highest Needs Review? (tick all that apply)

Other (please specify below)

Other relationship to the Review not listed above:  
Charity for all persons living with a rare disorder and their whānau

3 What is your ethnicity? (select all that apply)

European/Pākehā

Other ethnicity:

4 Do you identify as disabled?

No

5 What region are you based in?

Wellington

6 How would you describe where you are?

Urban

## What we would like to know

### Scope Area 1: The Journey Through the Education System

1 What is happening in your community that is working well?

Journey through education: what is working well:

For children living with rare disorders there are some examples that have clear need from birth and are visible, eligible and well supported.

We completed a survey that we late in 2021 and there were questions regarding education and the results are listed below (some of these points are for the next sections):

While most children of school age went to a mainstream school with or without adaptation, almost one in five went to a specialised school or had home schooling.

Almost 80% felt the rare disorder had a moderate to significant impact on their learning.

Overall there was a range of days that children were absent from school due to their rare disorder in a year with 23% children being absent for more than 30 days per year (see Figure 15).

2 What do you want to see happening?

Journey through education: What do you want to see happening?:

Common theme raised is that without recognition as a vulnerable and discriminated group the children with rare disorders will continue to slip through the gaps.

The need for recognition is paramount and this hopefully can lead to improved awareness and wellbeing outcomes.

As stated INCLUSION is vital for rare disorders; from this place individual education plans which factor the need of each rare disorder (following international best practice guidelines on that specific condition i.e. 22Q) will allow for clear balanced transition plans.

Transition plan to include options about employment support and family wellbeing during transition

QUOTE 'Invisibility of the conditions is a major barrier – lack of understanding and lack of access pathways'

3 How might barriers for learners with the highest support needs be removed?

Journey through education: How might barriers be removed:

From Voice of Rare Disorders Survey: -  
Many believed better Ongoing Resourcing Scheme (ORS) funding access would improve their situation, with 34% receiving ORS funding.

QUOTE 'What would improve the situation for my son is psychological assessment and increased access to learning support'  
Parent of child with rare disorder

Access pathways must acknowledge the rare disorder community or they can remain invisible and yet have diverse and progressive needs. This will ensure inclusion. For true wellbeing ecology a National Framework for Rare Disorders could allow integrated care plans across health and education including mental health support, environmental (CF can have cross-infection therefore need to be in different schools from one another) and workforce development so there could be experts made available, such as genetic counsellors to support the teachers as well as the parents.

## Scope area 2: Access to supports

1 What is happening in your community that is working well?

Access to supports: What is working well:

When there is a clear obvious need from birth and ORS funding has been established then care and support has been provided.

Sadly there are health needs attributed to the education challenges for many rare disorder children and there is a need to not ignore this fact. Rare disorders are often progressive, life-threatening and varied in progression of symptoms/impairment this makes assessment challenging. Changing the method of learning, adding technology aides and increasing understanding of rare conditions would make a massive difference.

Impairments caused by disorders lead to a need for support and a holistic view for wrap around care with a lifetime view would be ideal.

2 What do you want to see happening?

Access to support: What do you want to see:

Education for SENCO and TA's on rare disorders - this could be a simple 'Rare Disorders 101 module' like that for Mental Health.

Assessment for support must have understanding of the wide range of potential rare conditions and the complexity of challenges that this may present in the child. Obviously it is unrealistic to expect someone to know all rare disorder types however it is feasible to expect a basic awareness and understanding of rare disorders as a community. This will lead to improved outcomes for the children and stop some falling between the gaps. For example when there is a complex case which may not even have a diagnosis (average of 5yrs to gain a diagnosis) there is flexibility to include the voice of the parent or caregiver, medical specialists, or child's physician to ensure clear understanding of the specific needs.

QUOTE 'Some disorders are so rare that there is a lack of understanding and support'  
Issue=There is cumulative trauma for many of our community as constantly dismissed and even told 'its all in your head' and feel discriminated and shamed. Often asked to squeeze their child into a pre-determined box they do not fit.

Repeated assessment processes (reapplying when it is a life-time condition) lead to burnout for whānau and carers.

3 How might barriers for learners with the highest support needs be removed?

Access to supports: How might barriers be removed:

Changing the method of learning, adding technology aides and increasing understanding would make a massive difference.

Flags for children who have been circled through the system so they gain mental health guidance and support to prevent ongoing trauma. This would also apply to family and whānau. This is a missed area and will impact education and behaviour of the child (I know some māori schools offer a spiritual and mental health supportive model which could be replicated particularly for those with rare disorders).

## Scope Area 3: Responsiveness of Supports

### 1 What is happening in your community that is working well?

Responsiveness of services: what is working well:

Responsive action is not something that we see in the rare community as the messages we hear relate to a lack of diagnosis and lack of adequate support.

For example 'No funding offered to child, was not diagnosed until 13 and diagnosed at 14 but had clear needs for educational support'

### 2 What do you want to see happening?

Responsiveness of services: what do you want to see:

Clear awareness of the high uncertainty inherent in rare disorder community and ability to 'tick-a-box' when they have a rare condition to avoid being dismissed.

SENCO variability means that some disagree with parents requests for support due to a lack of understanding of the disorder and unconscious bias

Our hope would be for clear pathways and appropriate flexible assessment models so our rare community are included and gain responsive action for support.

System level inclusion for rare disorders and individual flexible view for specific rare children (tailored)

More consistency across all schools for children with highest needs. Or have specific teams that can attend and support across regions?

More training for key education professionals and assessors on rare disorders

### 3 How might barriers for learners with the highest support needs be removed?

Responsiveness of services: How might barriers be removed:

Supports could acknowledge the broader needs and impacts of the rare disorder on the child such as marginalisation and discrimination therefore factor in mental health support and guidance on resilience for both the child and whānau.

Clear pathways for responsive action as needed so support can be provided in timely manner

## Scope Area 4: Fluid Boundaries

### 1 What is happening in your community that is working well?

Fluid Boundaries: what is working well:

In some cases (not many sadly) there has been MDT and fluid boundaries for robust understanding of the specific needs of the child so the parent does not have to repeat the needs over and over to each teacher or TA they come across.

### 2 What do you want to see happening?

Fluid boundaries: What do you want to see?:

Flexible education options that incorporate diverse needs and the inability for some children to sit at a desk and focus for extended periods- this could include apprenticeships, clear pathways for practical skill based learning, nature brought into the picture for both the healing aspect and learning component (farming, gardening, herbs, etc). Employment support factored in for post secondary school which includes support for the parent who express intense strain during this time and overload of pressure when they are trying to help their child.

Alternative employment options with supportive care included offering purpose and social connections.

Inclusion of experts (peers or clinicians) so there are clear evidence based education plans in place that take account of the specific individual needs for each rare disorder type. This can lead to a major improvement in outcomes as evidenced in other countries.

### 3 How might barriers for learners with the highest support needs be removed?

Fluid boundaries: how might barriers be removed:

Improved inter-connection and holistic view for education that factors in all the other social determinants of health

Open communication with whānau and parents so there is ongoing dialogue and input across the whole life journey of the child.

Impacts on the child taking onto consideration and factored into education plans( operations -long term absences, procedures, medical appointments, physical issues that may lead to discrimination).

## Scope Area 5: Support for Adults Across the Network

### 1 What is happening in your community that is working well?

Support for adults: what is working well:

We feel we have already answered this question however as explained the parents who have children with clear distinct and already well understood conditions have voiced that with ORS funding or ACC support they feel things work well overall.

### 2 What do you want to see happening?

Support for adults: what do you want to see happening?:

Willingness to learn about rare disorders and how that specific condition is known to affect the child in order to best support positive outcomes and improved wellbeing

Specialist knowledge included as an overview for education plans including mental health support, genetic counsellors, paediatrician etc - this along with parent input and peer support from the respective rare disorder group to learn about what has worked well for other parents and whānau. There is also often best practice guidelines for many rare disorders that can offer clearer understanding and improved plans being established

### 3 How might barriers for learners with the highest support needs be removed?

Support for adults: how might barriers be removed:

Rare Disorders NZ could be funded by MoE to provide the central hub for SENCO, assessors, etc to ensure accurate and timely information - there could also be a training option incorporated for key education staff.

## Scope Area 6: Alignment Across Agencies

### 1 What is happening in your community that is working well?

Alignment: what is working well:

Not a great deal of positive to report in care coordination for rare disorder community as this falls heavily on the parents or caregivers and whānau and relies on individual ability, skill and capacity of them to manage (details of this are evidence in our white paper 'Voice of Rare Disorders NZ).

### 2 What do you want to see happening?

Alignment: what do you want to see?:

Recognition of rare disorders as population with evidenced needs so we can move into clear pathways of access, support and care

Having central facilitator for complex cases to guide and navigate the whānau

Systemic changes that incorporate alignment - Framework for rare disorders could offer this for our rare population and education is key component (also diagnosis, mental health, care plans, research, access to medicine, etc)

MDT models for combined discussion and inclusion of parents, whānau, specialists, etc

Communication plans established so that families remain informed at all times- common systems that inform parents with consistency across all schools

### 3 How might barriers for learners with the highest support needs be removed?

Alignment: How might barriers be removed:

cohesive care that includes all agencies would remove many barriers facing the rare disorder community- this needs a central facilitator or coordinator to be successful (SENCO or Key Health Professional)