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3 October 2024

Hon David Seymour
Associate Minister for Education
Private Bag 18888
Parliament Buildings
Wellington 6160
David.Seymour@parliament.govt.nz

Subject: Seeking Clarification on the 'Stepped Attendance Response' System and Its Impact on the Rare Disorder Community

Dear Minister Seymour

Rare Disorders NZ is writing to seek clarity on the recently announced 'Stepped Attendance Response' (STAR) system and how it will apply to children with rare disorders.

We understand that the new system aims to improve school attendance rates by implementing a series of escalating actions based on the number of days a child is absent.

As you are aware, children with rare disorders often face unique challenges that affect their ability to attend school regularly. We are seeking clarity about how the STAR system will account for the needs of these children and their families.

Rare Disorders NZ and our collective would appreciate you addressing the following questions:

1. Will the STAR system include current practice (as per MOE document *Guidelines for Schools around recording attendance*) that attendance/absence type *Medical Appointment – doctor or dentist* (school code D, reporting category P) is counted as present?
2. Will justified absences (for example: Student is at home, or in hospital, because of illness or other medical reason (including mental health days at the school's consideration) be counted towards the days absent in the STAR system?



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3. How will the system accommodate children who are unable to attend school full-time due to frequent allied health and other therapy appointments? Our rare disorder community has noted that these appointments often need to be during school hours as:
- Children with long-term health conditions and/or neurodevelopmental disorders are often exhausted by the end of a 'usual' school day and then unable to engage during the appointment a way that is beneficial.
 - There is not capacity outside of school hours for providers to deliver these therapies/supports to all the children that would benefit from/require them.
4. Will there be exemptions or special considerations for children with long-term conditions such as a rare disorder that may result in frequent or prolonged absences and/or prevent them from attending school full-time? If there will be an exemption, what will be the process to obtain it?

Families with children living with rare disorders already face a high administrative load and we ask that that it is prioritised that this load is not unduly increased in the development and implementation of any exemption process.

We fully support the intention to improve educational outcomes for all children, but it is critical that any policy takes into account the realities of living with a long-term health and/or neurodevelopmental condition like a rare disorder. Many children in our community already face significant barriers to learning and social participation, and we are concerned that a rigid application of the STAR system could place additional stress on families already managing complex health needs and the associated administrative load.

Thank you for your time and consideration. We look forward to your response.

Yours sincerely,

A handwritten signature in black ink that reads 'Chris Higgins'.

Chris Higgins
Chief Executive
Rare Disorders NZ