Highest Needs Review – March 2022

Submission by PWSA(NZ)

Scope Area 1: The Journey Through the Education System

1. What is happening in your community that is working well?
   For some children with Prader-Willi syndrome, a successful application for ORS funding is achieved well before they start school and parents therefore have time to look at school options, attend meetings with the school to discuss and plan supports, and to make preparatory visits. In these cases, transition to school will often go well. Future transitions also tend to go well as schools know that the pupil comes with an ongoing funding package and there are more school setting options available to pupils. The ORS package also provides for some transition funding before leaving school and enables pupils to stay at school for longer, which is most useful when social and emotional immaturity are typical in PWS. Some children have positive school experiences with their needs well catered for. They leave school well equipped for their next steps in the community.

   As PWS is a lifelong genetic disorder, ORS funding provides families and schools with some security due to its ongoing nature. Although the level of support will not always be the same, there is some reassurance that it will not be lost completely.

2. What do you want to see happening?
   The example above is of a journey through education where transitions run smoothly. This does not necessarily mean that all pupils with PWS who secure ORS funding have their needs understood and receive appropriate supports. (Details about support in further sections.)

   However, for many families, the journey is far from smooth. The journey through the education system may involve repetitive battles to access support, repetitive attempts at educating professionals to have their child's needs understood, a change of school or forced home schooling when problems arise due to inadequate support, and having to self-manage transition from school before a child is ready.

   What we would like to see is a genetic diagnosis like Prader-Willi syndrome factored into the journey through the education system and the supports provided. Whilst not all pupils with PWS have exactly the same needs and some will obviously need more support than others, PWS has a clearly defined cognitive and behavioural profile which could be used to inform a pathway of learning and could help to predict what future supports will be needed as a pupil moves through the system. Supports need to be responsive to need, but we also need a preventative approach to safeguard pupils from the damage caused when things are able to go wrong. It is not the time to apply for additional supports with extensive wait times when crisis point has already occurred. We know that learning, social and emotional gaps widen as pupils with PWS move through schooling, yet there is a general expectation that support needs should decrease as pupils become older. We see an increasing number of pupils with PWS leaving school early, but we would like to see all pupils be able to complete their education and graduate on a positive note, rather than at crisis point with deflated parents and teachers who have become tired of fighting the system.

   We would also like to see a willingness to learn about Prader-Willi syndrome across the system. We know that PWS is one of many rare disorders and would not expect all teachers to receive training in this syndrome, but we would like to see awareness and understanding of genetic difference and understanding of different learning profiles. We would like there to be an expectation that schools make efforts to understand and meet the needs of a recognised disorder when there is a pupil in attendance. We know that pupils with PWS do much better within a whole school approach and with consistency. An attitudinal shift is needed because it is too easy to place pupils in a too hard basket.

3. <u>How might barriers for learners with the highest support needs be removed?</u>

   - Improved assessment process to determine support needs taking account of diagnosis and the associated cognitive and behavioural profiles.

   - Improved assessment process that considers the complex, global and overlapping needs of pupils with disorders such as PWS.

   - An understanding that a disorder such as PWS is a lifelong condition requiring lifelong support and remove the requirement for schools to apply for renewal of funding and for parents to obtain medical certification that their child still has support needs (e.g. SHHNF).

   - Ensure there is equitable access to supports throughout a pupil's journey through the education system. It is known that chance of success at obtaining ORS funding is higher when applied for before starting school and the ORS application process makes it very difficult for older pupils to achieve once they are deemed to be doing 'too well' to meet a particular eligibility criterion. Whether a pupil receives ORS funding or not at a young age can depend on by whom and how an application was written and can affect a pupil's entire journey through school. A pupil with PWS who receives ORS and one who does not, may have similar needs, yet their journey through education will be very different.

   - The ability for schools to adapt teaching, learning and curriculum programmes so that they are relevant to diagnosis and need. This might be by utilising and modifying a pathway of learning (i.e. working toward mainstream curriculum standards may not be appropriate.)

   - Mandatory use of the I.E.P. process for all learners where there is a recognised diagnosis that is known to have significant impact on learning / behaviour / development. (We believe that only those who receive ORS funding are required to have an I.E.P. at present.) Reviews of targets and supports need to be ongoing and to occur more frequently - policy is needed around this. (Examples of expectation around I.E.P.s can be seen overseas.) Resources and support for teachers and SENCOs are needed to assist with creating meaningful I.E.P.s that are relevant to diagnosis and learning pathways.

   - Improved accessibility to therapies and interventions. A diagnosis such as PWS can determine which supports are likely to be needed. Children with PWS often access some early intervention therapies in the preschool years (PT, OT, SLT etc), with variable service provision and dependent on where they live. Access to therapies such as speech and language therapy then become non-existent during school years - this is a large area of unmet need. Another example of unmet need is the lack of available interventions to support social skill development which are typically deficient in PWS. Specialist supports and interventions are often limited to special schools and this expertise needs to be made more widely available and accessible throughout the journey through schooling, as need becomes clear.

   - Smooth transitions with protective supports in place to cushion learners who have difficulty coping with change. Transition from school funding and programmes for all pupils where their diagnosis means that life after school will not be typical. The PWS Association does not know of any adults with PWS in New Zealand who are able to live independently and very few who are able to obtain some form of employment without supports in place, yet about 1/3 of pupils with PWS do not receive ORS and therefore do not receive funded access to transition services.

   - Allowing for flexibility in school settings as needs change. Whilst children with PWS will have different needs in terms of the type of school setting that best suits them initially, it is very common for needs to change during their journey through school. We need to be prepared to respond to these changes and be able to act quickly before rather than after the 'wheels fall off'. If Government data were collected on rare disorders, some patterns and trends may have been seen, but through our connection with families and our knowledge of PWS research, we know that there are behavioural patterns which can typically occur. For example, it is usual for behavioural outbursts / loss of control to occur less frequently as children with PWS become older, but their intensity usually increases. We know that there is a high risk of mental health problems in adolescents with PWS. We know that social and emotional gaps widen leading to increased isolation.

- One of the key barriers faced is a lack of knowledge and understanding. We would like to see better trained teachers and SENCOs in all areas of special needs / learning support, but when a pupil with a rare disorder such as PWS enrols at a school, specialist knowledge is required. Schools could do this by linking to a national network where they could connect with other teachers, schools and advisors who have relevant experience and / or expertise. Learning pathways indicated by diagnosis could help with identifying possible needs and suggesting teaching strategies for success. There needs to be encouragement, incentive and expectations for participation in professional development that aims to improve the educational experiences and outcomes for children with learning support needs, especially those with rare disorders. The PWSA offers training in PWS to schools, but there is very little uptake and when there is interest, schools have little time to set aside for this and the training might only be for a few staff.

Scope area 2: Access to supports

1. What is happening in your community that is working well?
   ORS funding is ongoing and does not need to be reapplied for.
   Some pupils have access to early intervention centres such as WEIT and The Champion Centre.
   Some pupils can remain at school until 21 years and are better prepared for leaving school.
   Some pupils can access transition support services.
   There are some different schooling options available, including residential special schools (albeit with small intake and geographically widely dispersed.)
   Some pupils have positive educational experiences where a school has learned about PWS and taken a whole school approach to supporting their needs.
   There are pockets of good inclusive practice and these examples need to be shared.

2. What do you want to see happening?
   The funding application process to obtain learning support is too inflexible and restrictive. We would like to see this process take account of diagnosis and allow for the complex, global needs that pupils with PWS have, rather than expecting them to match rigid criteria and set descriptions. We would like to see the application process made easier so that it is not so time consuming for teachers who are often unwilling to apply if they think chance of success is slim.

   We would like to see equitable access to supports - it should not be seen as a fight for the scraps available and whoever fights the hardest wins.

   We would like access to supports that are responsive to changes in need.

   We would like access to flexible, multi-disciplinary supports that are inclusion focused, but also pupil and diagnosis driven.

   We would like to see more guidance for both families and schools around what funds and supports they should be receiving / applying for. Choosing which fund to apply for can be seen as a bit of a gamble - which are we more likely to be granted? which will provide the most support? which will best suit needs? which will last longer? One support may exclude access to another. Streamlining the supports available and allowing for an uncomplicated application process that enables schools to list all areas of need would reduce these uncertainties. It could be that a child's diagnosis helps determine what type of supports and level of support will be needed at different times throughout their schooling so that these supports are already available when and if they are needed. Access to specialist interventions, programmes or advisory services could be applied for separately or built into a support package where they can be triggered and activated as need determines.

There needs to be expectation around entitlement. Family stress levels are already high when raising a child with a complex rare disorder, without the additional stresses of dealing with multiple agencies and worries about whether their child will receive enough support, or if it could suddenly be taken away.

3. <u>How might barriers for learners with the highest support needs be removed?</u>
- The application process for support needs to take account of global needs as mentioned previously. It is well known that some pupils with PWS can appear to be much more able than they actually are, but it doesn't take much for things to go wrong when they live with high levels of anxiety and stress sensitivity.

- The application process needs to be both guided by diagnosis and pupil driven. Currently, a diagnosis can be a barrier to access because there is a lack of knowledge - it may just be seen as a health condition. Some needs can remain unrecognised and undiagnosed because PWS is a complex spectrum disorder and the umbrella diagnosis means that individual diagnoses are not made, i.e. dyspraxia, SPD, APD etc.

- The application process needs to be simplified and streamlined, but provide access to supports which are responsive, multi-disciplinary, flexible, and ongoing. The overly complicated nature of the support system creates barriers because it is unclear which fund to apply for. The application process itself is also a barrier because teacher time is stretched and there can be a reluctance to apply when there is such a small chance of success.

- The application process needs to be equitable and not somewhat dependent on luck (who applies, where you live, time availability of staff etc.)

- The ORS fund is too stretched. If pupils do not meet the restrictive ORS funding critieria, despite having significant learning support needs, there is no other funding option except School High Health Needs Funding (SHHNF). Many children with PWS who have been declined ORS funding, access SHHNF because they meet health needs eligibility criteria as a result of the need to keep them safe around food. The Teacher Aide time provided by SHHNF then has to be used creatively to support learning needs. There is no requirement for pupils with SHHNF to have an I.E.P., only a care plan. The SHHNF must be regularly reviewed which means that families and schools have to prove that their child still has health needs. There is also an expectation that the amount of funding should decrease as pupils learn to manage their own health needs, something that is not possible in PWS.
We should not have a system where pupils who have a complex, multidimensional, neurodevelopmental disorder accompanied by a diagnosis of intellectual disability, are denied access to learning support funding because they don't tick the right boxes and are left to make do with scraps of support that are entirely inappropriate.
We should not have a system where there are such disparate support streams. Health needs and learning needs do not need to be viewed so separately. We need a whole child evaluation approach.

- Fighting the system by reapplying for ORS several times and attending reviews where funding can potentially be unjustifiably reduced or lost can take its toll on families and schools. This creates a barrier because whilst fighting for supports, families become exhausted and can reach burnout, especially with such a focus on learning deficits rather than being able to set goals and celebrate successes. We would like to see uncertainties around qualifying for support removed. It goes without question that all children with PWS will need a level of support at school so this should be a basic entitlement that is individualised for each person.

- Access to transition from school funding and the ability to stay longer at school needs to be equitable and based on need. The majority of children with PWS present with developmental delay when starting school and they spend years trying to 'catch up', but the gaps only widen, especially during upper primary / college years. Readiness for leaving school will likely take longer and preparations mostly need different focus. However, many children with PWS are ill-equipped for life after school and this is often due to a lack of understanding of what that might look like, in addition to a lack of opportunities. Unfortunately, many children with PWS leave school before they are ready because their needs have not been well understood, appropriate supports are not in place, and behaviours have become too difficult to manage as a result.

- Supports provided need to be wide ranging and multi-disciplinary. Currently there are barriers created by whether a pupil receives ORS, whether they attend a special school and whether there is regional availability. For pupils with the highest needs, aspects of the curriculum may not be appropriate and there may be a higher need for goals to be set which do not have traditional learning focus. For example, this may involve physical therapies, mental health support, social skill development etc. A pupil may also benefit from access to specialised technology. Understanding of need is a barrier to success so it would therefore be of benefit if a team of people with the relevant knowledge and expertise were able to have input to decisions regarding access to supports. This team might include a physician, psychologist, out-of-area specialists, or a representative from a support group.

Scope Area 3: Responsiveness of Supports

1. <u>What is happening in your community that is working well?</u>
   Unfortunately, we do not see many examples of responsive supports.

2. <u>What do you want to see happening?</u>
   - Supports that are both strengths based and needs based.
   - Supports that are tailored to both diagnosis and individual needs, which have flexible long term and short term goals. Learning pathways that can easily be modified.
   - Curriculum relevant to needs. Supports which take a whole life approach and look at broader needs. Do the supports offered address the barriers a pupil is likely to face during education and post-schooling? The supports offered need to be based on appropriate expectation and equip pupils for real-life. They also need to factor in broader impacts on pupil experience, i.e. peer relationships, social isolation, mental health needs.
   - Wide ranging supports that include access to therapies and specialist intervention.
   - The collection of relevant data where measured outcomes can inform future support needs and curriculum planning, as well as track progress. Good use of I.E.Ps with routine reviews.
   - Flexible supports that allow for timely responses.
   - Inclusion at the forefront of support planning, plus supports which allow teachers to be spontaneously inclusive. It is not okay to just give a child something else to do to occupy them because they cannot do what others are doing.
   - Well trained TAs who are very able to respond to the needs of pupils with high needs.
   - Well trained support teams in schools who can respond to pupil needs, and specialist ministry teams to call upon when further advice or support is needed.
   - Improved avenues of complaint for parents when their child's needs are not being adequately met. Often, parent concerns are not met with responsive action and their complaints are dismissed.

3. <u>How might barriers for learners with the highest support needs be removed?</u>
   Responsive supports do not happen if there is a lack of understanding. There needs to be a level of understanding about high needs support across school teams: TAs, teachers, SENCOs, principals, and special education advisors. When a child with a rare disorder like PWS attends a school, additional training may be required. Schools should be encouraged to include and engage with parents regarding training because when a child has a rare disorder, the parents are not only their child's advocates, but

they have also become the experts in their care. As previously mentioned, in building a support team, schools also need to be able to involve others who work with the pupil in fields other than education. The Ministry of Education should also have teams available to help schools support pupils with rare disorders and high needs.

The availability and experience of TAs can be a barrier to pupils with high needs. We would like to see improved training and utilisation of TAs. It would be preferred if their role was seen as that of a learning support assistant who is trained to help respond to pupil needs rather than that of a teacher aide whose key role is supporting the teacher. It would be beneficial to all if there were more TAs in classes to help support teachers manage the diverse learning needs in their classes and these roles were separate to the role of assistants assigned to supporting identified pupils.

There needs to be an expectation that school boards can be questioned regarding their approach to inclusion and their responsibility for fully supporting pupils with the highest needs. Our self-governing school system and a lack of understanding at board level can be a barrier to pupils with high needs as their behaviours can easily be dismissed as unmanageable when there is little understanding of the struggles pupils might be facing and the supports that they need. It would be beneficial to all if training were compulsory for board members in developing an understanding of what inclusion means in practice.

Scope Area 4: Fluid Boundaries

1. What is happening in your community that is working well?
   Where good transition services have been provided, transition from school can go well, but unfortunately, there are limited employment and community participation opportunities available to school leavers with high needs.

   Some pupils with ORS funding have flexibility to choose where they attend school, but this is somewhat dependent on where they live and the choices available in their area.

2. What do you want to see happening?
   - Easier for teachers to access to relevant information, knowledge and expert advice held in specialist settings and at national level.
   - Easier access to specialist services / therapies.
   - Capturing of expertise held across agencies when necessary, i.e. involvement of clinicians, psychologists, mental health specialists.
   - A holistic view to supporting pupils with high needs.
   - Improved fluidity within the educational system that allows pupils to attend the setting that best suits their needs at the time, with an understanding that the appropriateness of that setting may change. For example, most pupils with PWS can do well in mainstream education with the right support, but for many pupils, this starts to change as they reach adolescence. Improved fluidity between mainstream, combined attached unit / mainstream, satellite classes, special schools, residential schools.
   - A consideration of what is in both the pupil's best interests and the needs of the family. In some cases, behavioural issues can become very hard to manage during adolescence which can greatly impact family wellbeing, including that of siblings. The role that residential schools can play in terms of providing a needed respite break for families is not considered enough.
   - Preparation for transition from school with realistic goals set for post-school life which have taken diagnosis into account.
   - Preparation for transition from school for all pupils with high needs so that school leavers and families are not left floundering and under strain.
   - Government focus on creating more supported employment / community participation opportunities.

3. How might barriers for learners with the highest support needs be removed?
   We think we have answered how barriers can be removed in the question above, by taking a holistic and cross-agency approach to providing easier access to knowledge, expertise, therapies and services, by improving fluidity between school settings, and by making improvements to the transition from school process.
   For these things to happen, a.) there needs to be improved channels of communication and a strengthening of connectiveness across the sector, and with external agencies; b.) schools and parents need to aware of what supports and options are available for pupils. This information might be outlined in a support guide (101) / pathway for pupils with rare disorders, like PWS.

   There also needs to be a greater cross-sector understanding of the typical challenges faced by pupils with rare disorders such as PWS. If there was better understanding of genetic difference, awareness of different learning profiles, and Prader-Willi syndrome was factored into support provision for a pupil's journey through the education system, parents would not have to repeatedly explain their child's needs so often to all the different people who work with them.

Scope Area 5: Support for Adults Across the Network

1. What is happening in your community that is working well?
   There are examples of teachers, SENCOs, principals and special education advisors who have been excellent in identifying and responding to needs. Some families tell us that they have been very happy with the efforts some schools have made to understand their child and to make them feel supported and welcome. Often, these are smaller primary schools where there tends to be more of a 'family' feel where pupils tend to be better known to all.

   Staff are able to cater better for pupils who receive ORS funding than those who do not because funding is specifically allocated to them. There are guidelines defining processes and entitlement. When pupils do not receive ORS, there is a battle for funding, but some schools are better at looking for and obtaining external support. Some schools make better use of their own budgets to prioritise pupils with special educational needs. There are some schools that do much better than others in being inclusive and providing good support which attracts parents to these schools.

2. What do you want to see happening?
   - Flexible and easy access to supports, services, knowledge, expertise, advice. Staff have the ability to promptly respond as appropriate when needed.
   - Frameworks and mechanisms in place so that staff know where and how to access and better meet needs. A less complicated and fragmented system that makes it easier to know where to apply for support rather than have so many avenues to try, each with their own pros and cons.
   - Connectivity and communication that encourages the sharing of expertise.
   - Professionals working together in multi-disciplinary teams.
   - Better use of specialists in their field who can work in advisory roles.
   - Teams may include parents, clinicians, mental health support, other specialists, national support group, national network data or contacts etc.
   - Collection of data and contacts at national level that can be used to help inform planning of supports and decision making. Easy access to useful information held at national level built on experience and access to a professional network where information can be sought from others with relevant experience.
   - Exemplification of learning pathways that can aid support planning.
   - Professional learning development encouraged, incentivised, and made available (outsourced if needed). A willingness to learn about a rare disorder such as PWS.
   - Professional development that focuses on: inclusion, strengthening supports, how best to utilise specialist advice and services, making the best use of TAs, developing meaningful I.E.P.s, 'outside the box' thinking in curriculum adaptation, removing barriers.
   - Improved teacher training that incorporates genetic difference and learning profiles.
   - Better use of funds that are available within school budgets.

- A system that enables staff (teachers / SENCOs) to easily monitor, then to assess and review supports and progress at regular set intervals. Sufficient non-contact time and support may be needed to lead / facilitate.

3. How might barriers for learners with the highest support needs be removed?
   This question has been answered already above. The result would be well trained, skilled, knowledgeable and effective school teams that are able to easily adapt and respond to needs. They would feel confident in being able to support pupils with high needs and supported in their work.

Scope Area 6: Alignment Across Agencies

1. What is happening in your community that is working well?
   We cannot give any examples of agencies working well together at present. Coordinating supports falls upon parents who must engage with multiple agencies.

2. What do you want to see happening?
   We have already answered this in previous sections by talking about collaboration with specialists, the sharing of expertise, communication etc.
   In summary, we would like to see MOE, MOH and MSD being easily able to work cohesively together in teams to support pupils with high needs. This also requires change in the health sector, in particular the development of a health strategy for rare disorders that recognises the complex and wide-ranging needs of this group. Multi-agency teams supporting pupils would likely need lead facilitator roles.

   We would also like to see this multi-agency, holistic approach extended into life after school with a seamless transition to adult services. An established multi-agency team working around the pupil could be mirrored in adulthood, for example within the Enabling Good Lives approach, a 'connector' could facilitate.

3. How might barriers for learners with the highest support needs be removed?
   As mentioned above, systemic change is needed.
   As we know of many deserving children who are declined ORS funding, we believe that many pupils do not receive either any or enough support through school (about 1/3 with PWS), which suggests there is a lack of financial investment in learning / high needs support. However, through multi-agency working, the cutting of red tape, the streamlining of funds, better trained teachers, and better monitoring of school spending, there may in fact be some long-term cost savings to reinvest.