



**2020 Review of the Disability Standards
For Education 2005
Submission by Diabetes Victoria**

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Introduction

Since 1953, Diabetes Victoria has been the leading charity and peak consumer body working, to reduce the impact of diabetes in the Victorian community.

We work to support, empower, and campaign for all Victorians affected by, or at risk of, diabetes. Diabetes Victoria values and respects the lived experience of people with diabetes. The needs of people with diabetes are at the core of everything we do. Refer to the [Diabetes Victoria website](#).

[Diabetes Victoria's 2019 Annual Review](#) presents the scope of our organisation's current activities.

According to the National Diabetes Services Scheme database, there were **3,556** school aged children with type 1 diabetes (foundation year to end of secondary level) attending Government, Catholic and Independent schools across Victoria as of 30 June 2020.

Diabetes Victoria's health professionals welcome the opportunity to present key concerns faced by students with type 1 diabetes and their families along with suggestions for improvement to be incorporated into the next version of the **National Disability Standards for Education**.

The focus of this submission is primary and secondary schools in Victoria.

For more information about type 1 diabetes the health condition refer to the National Diabetes Services Scheme (NDSS) Fact Sheet [Understanding type 1 diabetes](#).

Diabetes Victoria – reporting on the lived experiences of Victorian students with type 1 diabetes, their families and school staff

Since **2009** Diabetes Victoria has assigned health professional staff to develop a school's program for students, families, and school staff. Diabetes Victoria's schools' program and resources were funded by:

- National Diabetes Services Scheme
- In-kind support from the diabetes treating teams at Melbourne's two tertiary paediatric hospitals. i.e. The Royal Children's Hospital and Monash Children's Hospital
- Public donations to Diabetes Victoria
- The Victorian Department of Education and Training (DET).

Diabetes Victoria's health professional staff have daily contact with families and school staff regarding type 1 diabetes concerns.

We acknowledge many Victorian students with type 1 diabetes have enjoyable and engaging learning experiences whether attending our Government, Catholic or Independent schools.

Diabetes Victoria can point to several exemplars of best practice inclusion of students with type 1 diabetes from enrolment to graduation. However, these examples are not common or usual practice.

Regrettably in 2020, students with type 1 diabetes across Victoria still face direct and indirect discrimination, bullying, being singled out, stigmatised while at school and excluded from curricular activities. There appears to be a lack of consistent equitable funding to provide teaching aide support and disability resources for these students.

While type 1 diabetes is a disability at law i.e. Social Security, Victorian Equal Opportunity, and Federal Human Rights, this is often not recognised as such by the school. **This lifelong, complex, and invisible health condition requires consistent inclusion in forward planning for disability services, policy, and legislation in education.**

Statistics below from the Diabetes Victoria Advocacy Annual Reports for the last three financial years (2016- 2020) refer to the number of contacts made to the Advocacy team by families and school staff regarding concerns about the support for students with type 1 diabetes. This demonstrates that requirements are not well understood under the National Disability Standards to meet the needs of students with type 1 diabetes.

- 2016 – 2017 = 491
- 2017 – 2018 = 260
- 2019 – 2020 = 286 (with no contacts for 2 months while Victorian schools were closed due to COVID–19 public health restrictions)

Enrolment and access

Key concerns

- Direct and indirect discrimination at the time of enquiry about enrolment and at the time of enrolment at school
- Difficulty finding policy information about type 1 diabetes in Victorian schools
- Expectations of all parties is sometimes not clearly communicated. In particular there are unmet expectations of families that schools will make reasonable adjustments to support their child's diabetes needs to enable their participation in school the same as their peers
- Gaps in school principals and school staff awareness of their obligations for inclusion of students with type 1 diabetes under the Disability Standards for Education.

Quotes from lived experience experts

Students and families

“At time of enrolment school staff encouraged us to consider enrolling at another school. School leaders said their staff had no experience in type 1 diabetes and their budget was limited” – Government primary school.

Quotes from School staff

“Our school has never had a student with type 1 diabetes. This year we have a grade 3 student enrolled with type 1 diabetes. We want as much information and support as possible. Our school is in a low socio-economic status community and funds are very tight”– this is a consistent quote from principals, vice principals, and classroom teachers from primary schools, mainly government schools.

“Our school staff were anxious about having a child with diabetes at school (the school’s first experience with this condition) as they felt this was beyond their usual skill set and they did not want to cause the student harm. We applied for funding to employ a Learning Support Officer to support the student however this was denied”- principal of a Catholic primary school (Sept 2020).

Diabetes Victoria expert opinion

- Diabetes Victoria recognises that in the last two years the Victorian Department of Education and Training (DET) have consulted with stakeholders in the development of type 1 diabetes policies and guidelines for schools. In addition, they have funded the development and implementation of online diabetes learning modules to be used by all school staff. However, families and school staff have reported that they still experience difficulties accessing these resources on the Victorian DET website.
- Family groups continue to lobby for type 1 diabetes to be under a Ministerial Order as for other health conditions like asthma and anaphylaxis. Families remain convinced that an Order with a legislative framework will ensure ongoing /recurrent resources for staff training and teaching aides to keep their children safe at school.
- The Victorian DET has a gap in being able to know which schools have students with type 1 diabetes enrolled. This information gap hinders future disability service policy planning, implementation, and evaluation.

Suggestions for improvement

- Aim for a whole state approach for school enrolment information which includes clear information about rights and responsibilities towards students with disabilities including those with type1 diabetes.
- School principals to be proactive in working with families pre commencement at school (i.e. foundation years) or returning to school post new diagnosis of type 1 diabetes to support an application for a teacher’s aide (or Learning Support Officer) to support students with their diabetes needs.

- To undertake work to develop consistent, clear, and accessible information for families about type 1 diabetes policies, guidelines, and support programs in schools.

Participation

Key concerns

- Based on type 1 diabetes alone, students are being excluded from school excursions, school holiday programs, school camps and before and after school care programs.
- Some school staff are unaware their actions to exclude students with type 1 diabetes are contrary to current disability standards and laws.
- Some school staff are unaware that by excluding a student with type 1 diabetes from full participation in some school activities (the same as their peers), that it has a detrimental impact on the emotional health of the individual and their family.
- Students and families come to education with the expectation that inclusion of their child with type 1 diabetes is the norm. Sometimes they are sorely disappointed, distressed, and angry when exclusions happen.

Quotes from lived experience experts

Students and families

“The hospital has changed our child’s medical treatment to multiple daily injection on insulin. This means they will need to administer insulin at school. The school staff just freaked out about this. They just do not want to be involved in needles. They just do not get diabetes. All of this is stressing us out, my child is now reluctant to go to school, does not feel welcome and we are not sure what to do. All they need to do is have someone as a go to person and follow the action and management plan. School staff have talked about policies, guidelines and modules but when it comes down to it, they would rather we took our child to another school, we are considered a nuisance family now.”

“My son was told he could not do science practical experiments in the lab if he wanted to take his diabetes monitor and hypoglycaemia treatment with him. They mentioned something about health regulations. Being excluded from this class would mean he fails science. I just do not get it. Is it the case about health regulations? What are his rights here? – parent of government secondary school student in regional Victoria.”

This problem was solved by suggesting the student use disposal gloves and clear seal containers for diabetes hypoglycaemia treatments and equipment while in the school science lab. Health regulations were no excuse for exclusion.

“My 15-year-old son with an intellectual disability was told that now he has type 1 diabetes he is no longer able to come to a peer support group run by the local Council or attend any school holiday programs. He has been with this group for four years and he has made many friends; it is so unfair that he is being treated so badly. Now he has

two lifelong health conditions he needs more help not less to maintain his social, health and well-being.”

This matter was resolved within 20 minutes as Diabetes Victoria’s health professional staff advocated alongside the family to:

- *Organise professional development on type 1 diabetes for Council staff*
- *Have in place a personalised type 1 diabetes action and management plan prepared by this person’s diabetes treating team, the young person and family members. These documents gave Council staff, “go to information” on what to do and when re: diabetes health care tasks*
- *Know their rights. The family now has the contact details for the Victorian Equal Opportunity and Human Rights Commission along with the contact details for the Victorian Minister for Education and key Victorian DET staff.*

Mother of a year 9 boy at an independent boarding school was informed the day before outward bound camp that he would not be able to attend as the staff member taking the students refused to take a student with type 1 diabetes. The compromise with the school was that his mother travelled three hours from her home and slept in the car near camp to ensure her son could participate.

Primary school principal informed parents when they dropped their child off at school on the morning he was going to a 3-day camp that he would not be allowed to go as staff were not comfortable they could attend to his diabetes needs on camp. One of his parents offered to go on camp with him, however this was refused. This caused much anxiety and distress with the child, his parent, and the paediatric diabetes nurse educator, (DNE) who had been preparing and supporting the child, parents, and school staff, so he could go on camp. An urgent call to the Diabetes Victoria Advocacy coordinator from the DNE about the situation resulted in a call to the principal in which she was informed that this was discrimination and would be escalated to the Victorian Department of Education and the State Education minister. The outcome was the child and parent went on camp.

Quote from School staff

“While we have students with other health conditions, it is that those with type 1 diabetes that take most of our time across the school day. We need teaching aide support especially for foundation year students with an insulin pump and other devices. At foundation year these students are yet to learn how to read, write and recognise numbers which all are needed for type 1 diabetes management” – an example of consistent feedback from primary school classroom teachers, school nurses and school principals (Government, Catholic and Independent Schools).

Diabetes Victoria expert opinion

- Education settings need to have access to paediatric diabetes health experts to inform inclusion policies and practices.
- Diabetes management and self-care is changing due to an increase in the use of technology and evidenced based practice guidelines. However, schools on occasions have been slow to adapt to these changes. Some schools expect the student with type 1 diabetes to compromise their health care needs and change their medical care to fit in with the school staff needs. This is unacceptable.
- Gaps in policies at state level regarding administration of insulin at school.
- Paediatric diabetes nurse educators report that some school leaders make it hard for students to participate fully in all aspects of school life.

Suggestions for improvement

- To ensure all school staff who have a student with type 1 diabetes are aware that type 1 diabetes is a disability and is included under the requirements of the Disability Standards for Education.
- To ensure that families who have a child with type 1 diabetes are also aware of the above.
- To enable both parties to have access to information and online modules about the Disability Standards for Education.
- To allow access to the above information in an easy to understand format and in languages other than English.
- Make information about disability resources including funding more accessible across all school communities.
- Ensure that all school staff are aware, have access to and understand a student's current School Diabetes Action and Management Plan.

Supporting students

Key concerns

- Currently some schools are not asking students with type 1 diabetes and their families about what reasonable adjustments are required to support their needs.
- There is a lack of consistent documentation of the health support needs of students with type 1 diabetes at school.
- There are communication gaps between students, families, school staff and some health professionals about the student's type 1 diabetes needs at school.
- Schools need to be proactive in accommodating students with complex social health needs. Some students come from homes which are chaotic, unsupportive, whose parents/carers are dis-engaged. School can be the one stable, safe environment in that young person's life. With adequate support from the school, a student can still go on to achieve their full learning potential.
- Lack of disability funding across Government, Catholic and Independent schools.

- Sometimes the support needs of students with type 1 diabetes are forgotten. This comes about when the Victorian DET direct families to the school principal, only to have the school principal refer the family back to DET.
- Since 2019-2020 there has been a shift in funding support for teaching aide hours for students with type 1 diabetes by Victorian DET unless there are exceptional circumstances.

Quotes from lived experience experts

Students and families

“It would have been great if my year coordinator or principal would have just once asked me what it was like to live with type 1 diabetes. That is all it would have taken for me to feel wanted and respected as a person” – a struggling secondary school student.

“I felt okay at school once I had a teaching aide to help me” – primary school students newly diagnosed with type 1 diabetes – grades 2-3.

“The school asked us to fill out a Student Support Plan at the beginning of each school year – but there was no support. Our family was hoping to have a teaching aide even if it was for a term as my child has type 1 diabetes, plus anxiety and now coeliac disease. We filled out a lot of forms, got reports from medical specialists including from the Education Department’s own school psychologist but this request was knocked back by the Education Department. They seem to think we can all manage but we cannot, we only need some help until things settle down health wise so my child can be part of the class like their friends” – an increasing number of families with students attending Government Primary schools across 2020.

Quotes from School staff

“While we have students with other health conditions, it is that those with type 1 diabetes that take most of our time across the school day. We need teaching aide support especially for foundation year students with an insulin pump and other devices. At foundation years these students are yet to learn how to read, write and recognise numbers and all are needed for type 1 diabetes. It would be great if the Education Department made teaching aide funding and additional disability resources automatically available to schools to support foundation year students. This is the beginning of their education journey and it needs to work as best as it can so they can engage with learning” – an example of consistent feedback from primary school classroom teachers, school nurses and school principals (Government, Catholic and Independent Schools).

“I do my best to follow the student’s diabetes action and management plans that outline the health tasks that need supervision across the school day. I have found inviting students to check their blood glucose levels in a quiet place like the sick bay, first up at lunch break, I can check in on how they are travelling emotionally. Over the year I have developed good working relationship with students with type 1 diabetes, they can talk to me and we can head off any problems – health, education, relationships, communication and general growing up issues” – Government secondary school nurse.

Quote from Diabetes Treating Teams

“Clear communication and mutual respect are essential. This happens when social workers work collaboratively with school and student well-being staff to support students with type 1 diabetes who have complex needs” –paediatric social workers in tertiary hospitals.

Diabetes Victoria expert opinion

The Program for Students with Disabilities (PSD) is a targeted supplementary funding program for a defined population of students with disability and high needs.

Diabetes Victoria has received many contacts from concerned teachers and principals, families of students with type 1 diabetes and paediatric tertiary diabetes treating teams about recent information from DET that students with type 1 diabetes will not be supported under PSD. They have been advised to not put in applications for funding for teachers’ aides to support students with type 1 diabetes. This is particularly distressing for families and teachers with students in foundation years where diabetes needs are more complex. A young student is often unaware of how they are feeling, may have hypoglycaemia or hyperglycaemia, both considered diabetes emergencies. They do not yet have the literacy, numeracy, dexterity skills or the maturity to administer insulin or understand the results on a blood glucose monitor or continuous glucose monitor.

However, despite applications from families and schools and supported by experts recognising and pro-actively addressing the physical, cognitive, and social barriers that some students with diabetes experience at school they have been unsuccessful.

There are regional disabilities co-ordinators in each of the Department’s regions. Their role is to provide advice to schools about whether an application for the PSD may be appropriate in such circumstances, however they have been informed by DET that students with type 1 diabetes will not receive funding. As type 1 diabetes is classified as a disability this is direct discrimination of this group of students.

Suggestions for improvement

- Victorian DET to review and reinstate PSD funding for student’s with type 1 diabetes.
- Not confine access to school nurses to wealthy areas.

- Call for more school nurses to attend to the diabetes health care need of students with type 1 diabetes and other health conditions.
- Pilot an extension of school nurses across government schools where schools have students with complex social and health needs.

Harassment or victimisation

Key concerns:

- The use of [appropriate language](#) matters in diabetes and other health conditions. A person has a health condition, but it does not define their whole person. For example, the persistent use of the inappropriate phrase 'diabetic student'.
- Singling out of students with type 1 diabetes still happens
- Some students with type 1 diabetes do not feel safe and supported at school.

Quotes from lived experience experts

Students and families

Families reported their children with type 1 diabetes were told, “to wear a particular coloured hat across the school day and to stay close to the yard duty teachers so they knew where ‘the diabetic kids’ were at all times”– Government rural primary schools and Independent rural schools.

Students with type 1 diabetes were told during a combined school assembly “to come forward as the student with type 1 diabetes” so the students and school staff knew who they were. This was done by school leaders without any communication /consent /permission of the families or students - reported instances from Independent schools both in rural and metropolitan regions.

Taunts, teasing and bullying from other students via social media as the kid with diabetes, being called a “junkie” – mainly from Government secondary schools.

Families being asked to, “fund a Division 1 registered nurse as a requirement for their child to attend a school camp” - Independent schools.

Quote from School staff

“We keep the students with diabetes close to staff in the school yard and the classroom in case they have a hypo. We worry about our students with type 1 diabetes”– Government primary school teachers

Quote from Diabetes Treating Teams

Hospital based diabetes paediatric social workers report, “students with type 1 diabetes just want to fit in the same as their peers at school. Over recent years we have been seeing more upper primary students and those in year 9 with type 1 diabetes, being admitted to hospital because their diabetes has gone off track. This is often due to bullying from their peers at school. Some of these students have said that they want to die, and they feel very alone”.

Suggestions for improvement

- Ensure that type 1 diabetes as a disability is recognised in any education and inclusion policies to avoid harassment and victimisation at school.
- Ensure that students with type 1 diabetes have their privacy respected. The decision to inform their classmates or peers of their condition is one that is made by the family and the student, not by school staff.
- Any policies to prevent harassment or victimisation includes input from students with type 1 diabetes and their families.

Transition

Key concerns

- Transition from the Early Childhood setting to school is made more difficult for students with type 1 diabetes and their families as their previous funding for support does not transition with them.
- When a student with type 1 diabetes changes schools (for whatever reason), their previous funding does not transition with them e.g. shifting from a Catholic to Government School.

Diabetes Victoria Expert opinion

- Our experience has been that when families and students are going through a school transition process, diabetes policies, care and funding is not clear and transparent to them. This causes much anxiety, stress and on occasions conflict with the school.

Suggestions for improvement

- Granted funding follows the student from Early Childhood into the school sector or when changing schools.
- Promote inclusion for students with type 1 diabetes and reduce stress for families and school staff by initiating a review process for support funding rather than having to submit a new funding application.

Making a complaint - An example of a specific experience

A parent contacted Diabetes Victoria asking how to make a complaint to the Victorian DET as they felt the school had not met their obligations to their children with disabilities.

The parent had three children attending a Government Primary School in regional Victoria. All three children had disabilities, including one with type 1 diabetes.

This email was part of a complaint letter to the Victorian DET from the parent of these children.

Hi Susanne (Diabetes Victoria Advocacy Coordinator)

Sorry for the delay in reply but it has been quite hectic here.

Your email sounds good but there are some very serious points that I think need to be covered with X's lack of care as well as what occurred to his mental health as a result. I feel that the schools lack of attention and what I see as deliberate ignorance has placed him in life-threatening danger many times and caused him to enter a state of fight or flight. I think the best way to move forward is to list what I see as the biggest issues I had with the school and how they responded.

- Initially, X was in After School Care with both of his bigger brothers once a week. Even though they were well aware that X required a snack after school that had carbohydrates in them and this was explained to them on numerous occasions they couldn't seem to understand and were trying to give him low or no carbohydrate foods. I ended up having to leave a box of muesli bars with the after-school attendant so that he could access the correct carbohydrates in their care.
- 2015 X suffered a very bad low where he collapsed in the yard during recess. He fell, injured his elbow and was incoherent. His older brother, Y picked him up in the yard and carried him into the office screaming for assistance. Even though he was in-coherent they were able to get prima into him after a lot of work and get him back up to level. The school did not call an ambulance when they were having difficulty, they called me even though their action plan clearly states to call an ambulance, then the parent. When I arrived, he was getting back into the correct range with an icepack on his elbow and that is when I was advised that there was no ambulance called.
- 2016 both brothers entered high school and we began having difficulties getting X to school, he also refused to go to Diabetes camp, an event he previously looked forward to and did not want to leave. X was having meltdowns and began suffering extreme separation anxiety. He was petrified of going to school, I couldn't even get him to enter through the front gate. He would instead harm himself, he couldn't sleep, he hit his head, scratched himself with pens until he bled. He tried to take an overdose of insulin. Police were called and took him to the emergency department themselves. Youth Mental Health Service was involved, diabetes team at the local public hospital admitted him into the hospital to push the youth mental health service to medicate. His Psychologist visits were started again (and still run to this day) and all his anxiety and fear was centred around X's State Primary

School. With medication and 6 months of attending school with him, we were able to get him to attend on his own.

- Even though he was obviously in mental distress the school refused to answer calls from the public hospital diabetes social worker. They refused to speak with his psychologist Dr X they refused (forgot) to fill out forms for his paediatrician Dr X (only when I put it in writing at the beginning of Grade 6 Parent/Teacher interviews was a form completed). The only medical professionals they actually spoke to was youth Mental Health Service and I believe that is because they forced the issue. It was only when the diabetes social worker told them very clearly that they were failing in their duty of care that they agreed to meet with an educator, by this stage we were already in the process of removing X from the school.
- X was coming home covered in bruises and was complaining about being bullied by a child. When we tried to approach the school with the matter, they advised that the child in question had extra needs and that X was the bully, even though he was the one clearly covered in bruises. Upon later discussions with this Psychologist, when he felt safe, it came to light that this child was waiting at X's locker every lunch to hurt him. Therefore, X stopped eating lunch at school and would at times disconnect his pump. The school was aware that he was skipping lunch and he was supposed to go to the office and bolus and eat in the office, but this only happened sporadically. X's bullying was witnessed and confirmed by other children at the school.
- I picked up X from school and was advised by the office that X had "a little low". After school, I was contacted by another school mum asking if X was out of the hospital and if he was ok. I asked what occurred and she said her daughter (X's friend) was in the school yard and she saw X standing on top of the monkey bars then collapsed down and landed on his back. She walked over but couldn't get him to respond and "thought he was dead, he wasn't moving". She began screaming and a teacher came over, by this stage X was starting to come around. Apparently, he suffered a severe low, passed out, fell from a height, and then came to. At no time was I advised about this by the school or was there an ambulance called for the severe low, the unconscious episode or the hard hit after a big fall. X does not remember the episode.
- During Grade 6 X behaviour became increasingly worse and it was discovered he was attempting to get himself expelled from the Primary School. On his 1/2 year reports his behaviour was extremely bad. At the end of term two, we removed X from this school and sent him to another Primary School, after initially having a rough start due to heightened anxiety he settled in well and within 6 months he was learning again and his behaviour on his report was marked as excellent.
- You mentioned my middle son Z and his treatment with Dyslexia. I can still remember the moment very clearly; I think I was in shock. The vice principal had organised a meeting with the school psychologist to see if the school could get extra funding to "support" Z and his dyslexia. When the psychologist made it very clear that this was not financially supported by the government the vice principals' exact words were "I'm sorry but we can't teach your son". After the initial shock I advised them that if they could not teach them then they could not complain if I had to remove Z for a certain part of each week in order to have a specialist tutor come and teach him at home as he was embarrassed to have a tutor come to school and teach him there. We did this for the remainder of his primary school years, each week at a cost of \$60.00/week, and this is the only reason he can read and write.

In high school, they have made accommodations for him allowing talk-text and vice versa as well as allowing him more time during examinations so that he can keep up.

- Sorry for the long email, but I think the main points have been covered. X is still not friends with his diabetes, but we are slowly trying to rebuild his confidence in this area, just as we are slowly trying to rebuild his brother's confidence in himself. If I had to describe my children's experience in Primary School I would say it was shattering, it completely shattered the happy, confident young boys they were and it is only now in high school that we are occasionally seeing those young boys again. We still have a long, long way to go but I do not want to see any other children shattered by this Government Primary School.

Conclusion

Diabetes Victoria, together with the families that we represent would like to thank the National Disability Standards for Education 2020 Review board for the opportunity to present concerns and suggestions for improvements for students with type 1 diabetes to access and participate fully in their education.

We would be pleased to offer those undertaking the Review any further clarification or consultation of this submission.

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