



Australian Paediatric Society

Submission to Review of Disability Standards for Education 2005

September 2020

The Australian Paediatric Society (APS) represents regional Australian child health.

Regional paediatricians are very familiar with the issues of disability and schools. Regional paediatricians coordinate management of children with disability and their learning needs. Hence, they are frequently in contact with school staff, school support services and associated medical services. Managing this issue is a daily occurrence for almost all regional paediatricians. The gold standard is individualised management and the solutions may be specific to that specific region

The prototype disability that the APS has focussed upon in the last 6 years is Type 1 Diabetes. There are 62 regional centres and over 150 general paediatricians in regional Australia providing diabetes care to over 3500 children with Type 1 Diabetes (T1D) in Australia.

APS has been a very active in advocating to address deficiencies and inequities in the issue of management of Type 1 Diabetes in schools. Accordingly, the APS Diabetes Committee has developed significant expertise in this area.

1. ISPAD Clinical Guidelines and Position Statement.

APS support and endorse International Society of Pediatric and Adolescent Diabetes (**ISPAD**) **Clinical Practice Consensus Guidelines 2018 on Management and support of children and adolescents with Type 1 Diabetes in school.** (attached)

APS supports the **2018 ISPAD Position Statement on Diabetes in Schools (attached)** which had contributions from Australian parents, teachers, and health care staff. The Position Statement has been acknowledged as being legally sound and locally appropriate in Australia by leading legal experts.

APS recognizes the need to follow **best international practice** for children with Type 1 Diabetes. Accordingly, APS created the T1D Learning Centre in 2017 (t1d.org.au) which is a **cost-free smorgasbord of resources, including the International Award-winning e-learning modules** for school staff based on ISPAD guidelines and co-branded by ISPAD

The T1D Learning Centre also contains A Parent Guide to International Best Practice Type 1 Diabetes Care in Australian Schools (attached). This was developed in response to the confusion regarding the steps for successful integration of the student with T1D at school.

The guide comprehends Australian legal frameworks and the roles and responsibilities of those accountable for the student with T1D in the school setting. The guide is designed to inform and empower parents on the requirements of Education Providers and schools to comply with obligations to ensure Australian children with T1D are provided their fundamental right to access the highest standard of health care and associated management.

The APS, with collaboration partners, have also created a guide for clinicians to teach, train and implement best practice for integrating children with T1D disability into school. (attached)

Both guides encourage the crucial development of the 3-way supportive relationship between school, parent and treating medical team.

APS will not support **any amendments to ISPAD guidelines that may result in a lesser standard of care** for children with T1D at school.

2. Equity and transparency

APS strongly believes that funding must be **equitable, transparent and free of conflict of interest**. **APS has no conflicts of interest to declare.**

3. Legal Framework

The **Legal issues** around management of diabetes in school are **clear**, with only minor variations between states. However, they are **poorly understood and often misquoted**. The legal issues and required professional **code of conduct and registration standards** for medical staff and nursing staff are also not well understood.

APS is aware of past and current domestic and international legal actions taken when insufficient and inadequate management (such as refusal to deliver insulin at an education facility or provide authorised personnel to administer insulin) of children with T1d at school has occurred.

APS supports clear explanations of rights, role and obligations to parents, health care teams and school personnel.

APS supports the AMA position (May 2018) that is embedded in the AMA Code of Practice:

The National Conference requests Federal Council to advise the Federal Minister for Health that the Australian Medical Association insists it is the treating doctor's primary role and responsibility, in collaboration with and with informed consent of the parent, in training school staff to administer the prescribed medical treatment (including insulin and glucagon) and manage complex medical care for their child with Type 1 Diabetes on their behalf. The content of the training is individual to the child with Type 1 Diabetes and is solely the responsibility of the medical team and parent.

4. Individualised care

APS recognises the need for **individualised care** for children with T1D at school. The health team has a responsibility to ensure clear instructions to the school for their prescribed treatment through a Diabetes Management Plan and both education and training (level 2 and 3) delivered by parent, health team or a combination of both.

Any **3rd Party** who has **no responsibility for clinical outcomes** and does not have **parental consent** **MUST NOT** give clinical advice on the individual. **Prescribed medical treatment** **MUST NOT** be changed by a **3rd Party**.

5. Application to other Disabilities

The International Society has endorsed both the Parent Guide and Clinician Guide, and both are accessible on the ISPAD website. The RACP Policy Committee is currently reviewing the resources to become part of RACP policy for generalisation to other disabilities. One senior developmental paediatrician assessed the documents as *“I am in admiration of the work that has gone into this. It is comprehensive and considered. I am somewhat envious also of the organisation behind this, and the capacity to do so much practical good.”*

6. Effectiveness of Disability Standards

The APS recognised the non-compliance of the rights and obligations of children with T1D in 2015 and advocated for change with the Federal Government, establishing the original Diabetes in Schools program in 2017. Unfortunately, the process was derailed, and APS sidelined because APS would not accept changes to the program introduced by an organisation that did not want their own programs to be defunded. Those changes would promote and force fund lesser standards of care, and non-compliance with informed consent and privacy. Moreover, the publicly funded legal reports that supported the APS position were never disclosed and remain hidden.

As a result, APS decided to create not-for-profit resources based upon the best possible international standards and ensure families education providers and policy makers knew about their rights, obligations, and measures of compliance.

The Review of the Disability Standards should be aware that some publicly funded entities profit from non-compliance to disability legislation. This is not in the best interest of children with disability at school

SUMMARY

The APS has recognised the non-compliance of many schools with disability law and avoiding the reasonable adjustments to allow children with disability to partake in school activities on the same basis as their peers.

The APS, with the unique experience of medical expertise and school exposure and experience, has taken significant steps forward to develop sentinel advocacy documents and resources to assist children with disability at school (t1d.org.au). These principles are locally appropriate and legally validated. The learning modules to upskill school staff have been awarded the 2019 international ISPAD prize for diabetes innovation.

The APS resources are being generalised to other disabilities in school and APS is prepared to partner with the Federal Government to assist the disability Standards for Education.

The APS documented guidance and training programs have been based on the rights and protections that exist under the Disability Standards for Education. The Standards are well understood. The biggest issue for students with a disability is the deliberate lack of compliance to these standards by education providers and their delegates.