SUBMISSION to 2015 REVIEW OF DSE.

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STUDENTS WITH SERIOUS & CHRONIC ILLNESS– A GROUP OF DISABLED STUDENTS IGNORED.

What has been your experience of access and participation?

I approach this from multiple perspectives, as follows;

• My overwhelming experience in each of the roles outlined below have been that students with serious and chronic illness are consistently overlooked as requiring either Disabilities Funding and/or support or Disabilities Provisions in schools and education systems.

• I am a parent of a childhood cancer survivor and have had to negotiate the education system from this perspective.

• I am a teacher with 35 years’ experience, and spent the last 12 years specialising in working with students with Individual Needs, particularly those with serious/chronic medical conditions.

• I am a Type 1 Diabetic- (diagnosed 45 years ago) and have lived with medical disability most of my life.

• I was awarded a NSW Premier’s Teachers Scholarship (2011) to study Strategies to Support the Learning of Students with Serious Illness. (see several reports online published under my name).

• In 2012 I convened and presented my findings in a regional Central NSW forum for parents, educators, health
practitioners & students to share my knowledge and gather insight to the status of local experience in different education systems.

- I was a contributor to the 2011 Review on the DSE, via the submission by Ronald McDonald House Charities.

**The composite of my professional, personal and research experience is summarised below:**

- Medical disability/serious illness remains uncatered for in most schools and education institutions. If the medical disability is not physically obvious, the issues remain “invisible” to teachers and the school system. The presumption by teachers is that medical issues are fixed by health practitioners and that so long as the student’s actual health is not compromised at school, the issue is not seen as an educational one. There is little to no understanding of the degree to which learning is compromised in these circumstances.

**Is the community aware of barriers faced by people with disability?**

- Teachers and educational communities remain ignorant of the need to make educational adjustments for these students because they do not understand the complexity of the student’s needs and the impacts those needs have on learning.
- Issues of pain, general ill health, absence from school, fatigue, medication impacts, psycho-social challenges (eg. Anxiety) all impact on students’ ability to learn.

- Education Authorities in Australia do not specify or clearly mandate policy or funding for learning support for the medically disabled.

**How helpful are the standards for educators and education providers?**

IN PRACTICAL TERMS, THE STANDARDS ARE NOT HELPFUL AT DETERMINING GOOD PRACTICE.

- The Disabilities Standards of Education provide little more than a theoretical framework which serves no practical purpose at school or educational system level.

- Schools and education systems with which I have been associated pay only cursory attention to the DSE. Awareness is limited to circumstances where the disabilities are visible, clearly funded and around which there are legal precedents in Case Law.

- Medical disability funding criteria in Australia is not mandated explicitly. Disability Provisions for public examinations in schools is ALSO not automatically mandated
for students with serious or chronic illness. In both the areas of funding and Disabilities Provisions, each case requires specific advocacy by either a parent or interested member of the school staff. This advocacy is carried out only in rare situations because;

- Most school staff don’t understand/are unaware of the learning issues.
- Parents of seriously ill children are under significant emotional, physical and financial stress- and simply cannot face the battle with bureaucracies.

All the physical research I have undertaken and read, and my personal experience show that **funding and/or Disabilities Provisions for chronic and seriously ill students is very difficult to access.**

- In the case of Disabilities Provisions for public examinations, most states rely on a standard (tick box) criteria for medical issues. These are focused on **mobility impairment, hearing or vision impairment.** This completely eliminates the bulk of students whose medical condition fails to fit these narrow criteria. Following is a list of the common serious illnesses that are automatically overlooked by schools and education systems;
  - Epilepsy, Cystic Fibrosis, Crohn’s Disease, Severe Asthma, Cancers, Blood Disorders, Heart conditions, Juvenile Arthritis.
- This list is not comprehensive, as there are too many chronic/serious illnesses with significant physical and psycho-social impacts to list here.
• Parent histories of this issue reflect that when detailed medical evidence is provided in the form of a “case”, occasionally provisions are made for public examinations. Yet, each is dealt with on a case by case basis. The outcomes are inconsistent at best and require significant advocacy by parents who are already stretched. This is a clear form of discrimination.

WHO CHECKS THE Disabilities Standards of Education ARE BEING MET?

Given that it is the individual State Curriculum Authorities (eg. BOSTES in NSW) who hold the power to register schools, and it also falls under their authority to administer Disabilities Provisions for public examinations, it is reasonable to expect that the same authority would be responsible for a) mandating and b) checking compliance of schools and education systems to meet the DSE.

** I have participated in 3 school registration processes at an Independent School in NSW. In none of those processes was there any request by BOSTES to investigate or check the school’s Learning Support programs, practices or policy. At no stage were the Disabilities Standards of Education on the agenda. (The last registration process I was involved in was 2014).

This would indicate that despite the existence of the DSE, if there is no authority charged with the direct brief of checking school and education system compliance, or policing it, nothing will happen in practical terms at school levels.
In NSW Catholic Systemic and Independent Schools there has been no follow up of compliance. DEC Schools in NSW are expected to comply as part of Government Policy yet, again, I have found no evidence of a process of checking compliance.

**Are the standards a useful tool for advocacy?**

- In theory, the standards are simply a tool, nothing more. **In practice, however, they are useless without an authority overseeing school and education system compliance.**
- The DSE are also useless without the explicit inclusion of students with medical disability/serious illness. This is necessary because of the historical omission of this group. If they, as a cohort are not specifically noted, then they will continue to be overlooked for provisions and funding.
- The Nationally Consistent Collection of Data carried out in recent years has been a flawed process for the purpose of catering for Seriously Ill students.
- The Data Collection process relied on “teacher referral/identification” of students with disabilities. If students were not actually already receiving support for a disability at the time of the data collection, then there was no requirement for them to be included in the data.
- This was a deeply problematic process as, historically, medically disabled students have NOT been included by teachers as either requiring or receiving Disabilities Support. **Thus, it has become a vicious cycle of non-recognition.**

**How can we improve the effectiveness of the standards?**

- Explicitly mandate a Government Authority in every state and
territory to check school and education system compliance with the DSE.

- Specify Medical Disability within the DSE and within the brief of the Government Authority charged with overseeing compliance.
- Carry out meaningful penalties against any educational institution failing to comply with the DSE, (based on the DDA).
- Remove narrow tick box criteria for disabilities funding purposes, thereby broadening the access to assistance.
- Mandate the training of ALL serving teachers and University Education Faculties to undertake/provide training in the educational support of ALL forms of Disability- explicitly including Medical Disability.
- Mandate the State Departments of Health and Education to communicate more openly with each other to facilitate clearer, more appropriate professional communication to support the learning needs of students with serious illness.

**SUMMARY**

The level of research already published and the growing numbers of students surviving serious illness due to medical advances present a compelling case for meaningful changes in policy and practice in the educational support of these young people. Continued bureaucratic and policy failures to implement even the most basic systemically funded supports for this cohort of disabled students are a glaring failure. This can only lead to the conclusion that governments are, by neglect, in breach of the Disabilities Discrimination Act of 1992.
Just as previous actions have been undertaken against State and Federal Governments on the basis of inequities, it is inevitable that at some stage, advocates and parents of seriously ill (and thus, medically disabled) students will turn to litigation as their only remaining pathway to instigate change and financial equity. This is especially so, given the level of research and growing evidence of economic disadvantage that results from serious and chronic illness and its educational sequelae. Governments, policy makers and bureaucracies would do well to instigate meaningful change based on existing guidelines (the DSE) and laws (DDA, 1992)- prior to the development of a climate of militancy among the advocates and survivors of this group of disabled young people.