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The Secretary,
Senate Employment, Workplace Relations and Education References
Committee
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Dear Secretary,

I have a few quick points to make on the Education of Students with disabilities.

Criteria Used to Define Disability

It is my understanding that definition of disability is shifting to include chronic illness. It was extremely troubling to hear from an Education Department Official that they "can get a couple of million dollars for a school to install an elevator for a kid in a wheelchair, but couldn't get the money for a beanbag for a chronically ill student to rest in the library."

Such inflexibilities in the inclusion criteria for disability are naturally absurd. I would hope it is self-evident that the spirit of anti-discrimination legislation enacted for those with traditionally understood physical and mental disabilities, should also apply to those with chronic illness. I hope this enquiry goes a long way to ensure that these inequalities are addressed and chronic illness is taken as seriously as other 'difficulties,' and that our definition of disability be broadened to incorporate the chronically ill.

Chronic Illness is as much a barrier to education as any intellectual or physical issue that has traditionally been thought of as a 'disability' or 'handicap.' Students with chronic illnesses, through no fault of their own, are not able to learn as much and in the same ways as 'healthy' students. Chronic illness affects the ability of students to attend school, it affects the volume of work they can take on, and the speed at which they can learn and account for their learning.

Our Society represents people with Myalgic Encephalomyelitis or Chronic Fatigue Syndrome. This condition involves various neuro-cognitive symptoms such as difficulty with short term memory, concentration, finding words and performing simple calculations. Such symptoms are often affectionately referred to and summarized as 'brain fog' - a cloudy head. These symptoms are clearly problematic for any student. As is the most obvious symptom, fatigue, which may prevent a student from being able to attend school full-time. A more obscure symptom such as orthostatic intolerance (low blood pressure) may also affect a student considerably if he/she is forced to stand for any activity. So too for symptoms such as sensitivity to light and noise - these pose difficulties.

Possible Accommodations

Understanding the symptoms and nature of any chronic illness is essential to determining which accommodations will benefit the student, and which ones won't.

Chronic Illness may require accommodations different from other disabilities, and may require us to think about them in totally different ways. Persons with CFS, for example, would benefit from a quiet room where they could lay down in between lessons and during breaks. As mentioned above - a beanbag might even do the trick.

Accommodations for chronic illness revolve around helping the student by cutting out all unnecessary, extraneous commitments out of their schooling. ie requirements to stand and attend assemblies or to do PE. It also involves judicious determination of when the student actually should be required to physically attend lessons.

When it comes to testing and examinations the classic accommodation suggested is 'give them more time' but this is totally unhelpful to a student with chronic fatigue syndrome. 2 hours may be their limit - after which they are too mentally fatigued. A more sensible solution is to spread the exam over 2 sessions.

Another common accommodation is to let students type up exams on a laptop, as this is often less draining than writing.

In extreme cases examinations might not be possible - the mark for the year's work may need to be used instead of an exam mark.

Common Scenarios

I thought it would be helpful to describe just how some CFS students get their Secondary education. These are based on individual cases I have known - bear in mind these are the 'good examples.' Not every student is fortunate enough to have a school willing to accommodate their needs; not every child has a parent able to negotiate adequately.

Students with CFS often do not attend school full time. (Many do home schooling.)

- 1) Some students attend mornings only - and take the rest of their work home
- 2) Some students may attend alternate days
- 3) Some attend only critical lessons
- 4) If they are quite unwell, their school may remove all 'unnecessary subjects' - honing in on the key Maths and English educational components. This is helpful.
- 5) Most do not do a full load of years 8-10
- 6) Most do years 11 and 12 part time (2 years each)
- 7) Some students start year 11 in year 10, to try to get ahead
- 8) Some students are only able to do 1 home-school subject per year
- 9) Some may do a combination of school and home-schooling

It is not uncommon for students with CFS to be still trying to complete year 12 when they are 20 years old.

Students unable to properly complete years 11 or 12, if they are bright, can get approval to sit the University Stat tests to gain entry as young as 19. The Universities should be commended for this.

Teacher Training

Teachers play an important role in including students who may have special needs. It is vitally important teachers take an active interest in such students - if they take the time to understand

their difficulties they will not only be in a position to predict troubles ahead of time but they will communicate acceptance of the student to the rest of the class.

Rules for Completion Year 11 and 12

In South Australia there seems to be a rule that dictates students finish years 11 and 12 over a maximum of 2 years each. It is our belief this time imposition is purely for the benefit of administrators and there is no reason why it should be in place. There is considerable inflexibility in these rules.

Criteria for gaining year 11 and 12 should be more flexible. The number of subjects should be able to be reduced and / or students be given the dignity of being able to complete them over 3 years.

It is important we remember why we have schooling and an education system. It is there to provide a framework for the development and learning of every young person. Students with chronic illness, like those with traditional disabilities, may have limitations, but it is imprudent to make life any more difficult for them by imposing 'false norms' on them. By the age of 20 it is important that our youth can function and operate in Society.

Intelligent children, despite chronic illness, can achieve this goal without having done every subject or taken part in every school activity. They should be allowed to be credited with year 11 / 12 if they have done what they can given the obstacles they face. This is not cheating the other students, if the child's ability to learn and achieve acceptable results is only hampered by the time they can put in. I would therefore propose that 3 out of 5 subjects should be sufficient to complete these years.

Role of State in Enforcing Legislation / Policies Required

Current South Australian Education Department policy is to make 'non-directive' recommendations for accommodations. It is the responsibility of individual schools to deal with students on a case by case basis, and to suggest accommodations to parents. It is the parent's responsibility to negotiate with the school.

We would argue that this is inherently discriminating against the student and their family - there is a power imbalance in this system and a conflict of interest for the school.

Schools are not required up front to provide guidelines for parents on how they can go about securing accommodations for their child; both to ensure they have an equitable chance of obtaining an education, and they have a fair go when it comes to assessment. Until parents are explained this ahead of time, and there is a well-defined process, the entire system is ad-hoc.

The schools are placed in a difficult situation in that it is not in their interest to be transparent and open about the possible accommodations that could be made available to various students. Accommodations naturally create more work and schools are stretched. So why should they go out of their way to make known possible accommodations to potentially 'special needs' students?

Well-educated parents stand a better chance of arguing their case; those with poorer education and professional life-experience may not have the verbal and research skills to get as far.

To remove this conflict schools should be required to have a process whereby parents can negotiate for accommodations. Material must be readily available - explaining their rights and giving examples of the sorts of accommodations that are possible, and the fact that any reasonable suggestion they make needs to be taken seriously. There needs to be a hotline in

every State for parents to seek assistance should they feel they are not receive appropriate accommodations and support from their school.

Conclusion

I hope this has given to you some insight to the issues facing people with Chronic Fatigue Syndrome - I'm sure it is directly applicable to many other chronic illness which don't necessary affect IQ, but reduce the quality time the student has for education and learning. I commend the formation of this committee and process, and hope it will serve to improve the education of those with any disability.

Yours sincerely,

Paul Leverenz
President
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