

**Submission to the Review of the NSW Board of
Studies, Teaching and Educational Standards**

A Case Study in Disability Adjustment Provision

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Context and relevance to the 'Issues Paper' of 31st March 2016

The attached case study was originally submitted to the Australian Federal Government Education and Employment References Committee Inquiry: *Current levels of access and attainment for students with disability in the school system, and the impact on students and families associated with inadequate levels of support*. That inquiry was held in September 2015.

The relevance of this submission to the current review of BOSTES is specifically in relation to issues raised in item 3, p.5 of the issues paper regarding processes and practices and to the issue of quality more generally.

The submission raises questions about the fairness and equity in facilitating disability adjustment provisions, but also about the need for BOSTES to engage in best practice for issues around disability - especially in the practice of inclusive decision making in relation to the people who experience and have most intimate knowledge of their own disabilities.

As the author of the case study, I am happy to provide further input to the deliberations of this independent committee and welcome the opportunity to make this submission.

Mick Houlbrook, 21 April, 2016.

A Case Study in Access.

1. Preamble

This case study describes the experience of one student and his family seeking disability adjustment provision from the Board of Studies, Teaching and Educational Standards (BOSTES) NSW for Higher School Certificate (HSC) examinations. While the application was successful (upon appeal), for the student concerned, the journey undertaken shed significant light on a number of barriers, and potentially inequitable issues in the process and provision of disability adjustment. The case is used to point out these things and to pose a number of questions about disability adjustment, in keeping with *item h.* of the terms of reference of this inquiry, namely:

What should be done to support students with a disability in our schools?

2. Introduction

In order to facilitate equity, students in NSW are able to apply to BOSTES for disability adjustment provisions for HSC examinations. The process involves application by specific dates, through the school and students and their families need to provide appropriate evidence of the existence of the disability as well as its impact on performance and the kinds of provisions that would ameliorate the its effect. Applications that are not upheld in the first instance can be appealed, within three weeks of the decision from BOSTES, but only on the provision of 'new information' relating to the disability. This case is based on the experience of Mark and his family seeking disability adjustment provisions in relation to Tourette's syndrome. Apart from the presence of tics, verbal and/or physical, Tourette's can impact on muscular fatigue and fine motor skills – thus having a direct influence of both legibility and speed of handwriting.

3. Case Description

Mark* is a popular young man who is active and involved in a number of things, from sport to social issues. He has an older sister at university, a father who is an academic and a mother who is a senior public servant. The family lives in the Inner West of Sydney and is comfortably off, in the top 5% of household income distribution. He is aware of his relatively privileged position and that many other people are not so well off.

Mark was diagnosed with Tourette's syndrome in year one of primary school. Though he has significant verbal and physical tics, he has managed the effects of his condition with little impact of his social progress at school. Indeed he was school captain at both primary and senior secondary school. The impact on his fine motor skills however, has been significant and his

* For the purposes of this submission Mark is a pseudonym.

handwriting is poor. His writing is difficult to read and very slow. While Tourette's syndrome is often associated with other conditions, such as ADD, ADHD and OCD, Mark has none of these.

Mark's schools have been aware of his Tourette's and, by and large, have accommodated his handwriting issues. In later school years he has been more able to access a keyboard for the production of much of his schoolwork. The one area of concern is exam conditions that traditionally rely on fast, legible handwriting for successful, accurate representation of a student's ability. For this reason Mark applied for disability adjustment provisions in HSC.

The assessment

Confirmation of Mark's diagnosis of Tourette's was provided in evidence and Mark was also assessed by a senior occupational therapist. During a lengthy assessment Mark wrote and typed full-length essays from his subject curriculum under examination conditions. In the assessment Mark was categorised as being in the third centile for writing, i.e. below 97% of his cohort. His typing brought him closer to his cohort, being 23 words per minute as compared to an average 35 words per minute for his peers. The report also highlighted the following points:

Mark remained focused, cooperative and polite throughout the assessment. He was observed to have the following difficulties: [detail excluded]

- Poor volume of writing over extended periods*
- early onset fatigue*
- Poor manual dexterity*
- Poor letter formation*

The recommendation included:

Hence it is most strongly recommended that he uses a laptop when writing extended responses and that he is granted extra writing and rest breaks of at least 7 minutes each per half hour for those assessment tasks where the use of a laptop is not feasible so that he can attempt his responses at the same level as his neuro-typical peers during the HSC exams. [Emphasis added]

The application for disability adjustment provision

On the basis of the reports and Mark's own experience of what worked for him, an application for disability adjustment was made through the school (as required by BOSTES procedures). This application sought the provision of laptop computer (adjusted in terms of spelling checking programs etc.) with appropriate rest breaks to ameliorate the effects of fatigue. The initial application was rejected – the notification was delivered to Mark by email. The actual provisions offered were 2.5 minutes extra writing time per half hour and five minutes rest per hour. These provisions were nowhere near those recommended by the professional assessment of Mark's condition. From that point substantial efforts were made to appeal the decision; some interim

concessions were made (specifically the provision of a scribe), outside the proscribed policy, but not in keeping with the original application. The formal appeal was upheld by BOSTES granting the original requests, however the experience highlighted a number of concerns that go well beyond the specifics of this case and, in particular have significant ramifications for equity. On that basis the following section takes some of the experiences of this case to argue the urgent need for changes.

4. Reflections on BOSTES Disability Provision Processes

The case highlighted a number of concerns; some were specific to the circumstances and relate to individuals, but all the experiences listed have general application to the principle of equity and the business of treating disability seriously. Several themes are drawn out of the experience below.

Theme 1 Compliance and resistance

Mark and his family strongly experienced a culture of rigidity in the handling of application for disability provision. There is a lack of openness and transparency and unwillingness to explore concerns and anomalies in relation to evidence. For example there is no provision for appeal on the basis of BOSTES making an unfair or erroneous deliberation. The experiences were characterised in the following ways:

- **What BOSTES says** – the experience of Mark and his family was that there was a strong culture of compliance with what BOSTES says. School staff reported a BOSTES seminar where there was a strong assertion that the provision of laptops would not be provided, except in the most limited cases. This flies in the face of treating each case on its merits.
- **Negative disposition** – the adherence to generalised assertions from BOSTES created a discouraging approach to Mark's application and in the initial rejection of the laptop request, elucidated an "I told you so" response from the school. This not only increased Mark's anxiety and frustration, but also led to his parents insisting that communication was made through them.
- **Discouragement from seeking higher input** - BOSTES appears to operate in a near fortress-like state and contact for information is actively limited to and channeled through the school; yet in Mark's case direct contact with BOSTES was crucial in clarifying aspects of the application and errors in assumptions made about his assessment.
- **Poor communication and information** – there is no explanation for decisions made or for appeals to be based on such errors. However, in direct contact with BOSTES it was clear that assumptions about the evidence in assessments in general did not match the specifics of Mark's case. In particular BOSTES senior staff seemed to have a general impression that assessments of handwriting were inadequate and 'light on'. Mark's assessment took seven hours over two sessions and involved writing and typing whole essays from his curriculum, under exam conditions. This gave the impression that BOSTES was indeed following its own generalised perceptions rather than looking to the evidence of specific cases. It must be noted, however, that the demeanor of BOSTES staff in conversation was, positive, sympathetic and professional.
- **Minimal recognition of parental involvement or interest** – the initial rejection of the request was via email to Mark. Along with the insistence on application being only through schools and discouragement regarding contact, there is a strong sense that parents are not welcome to have active input.

Theme 2 Focus on a culture of entitlement

The experience of applying for disability adjustment provisions had a strong sense of being judged as imbued with 'entitlement' on the part of the applicant. In specific terms this was manifest as:

- **Feeling like it was 'asking a lot'** – asking for a laptop felt very much like it was excessive, despite the recommendations of the highly respected professionals who assessed Mark. The idea of rejecting a 'scribe' (an offer made outside the formal process after contacting BOSTES to discuss the inadequacy of the original provisions) in preference for a laptop seemed to be seen as ungratefulness on the part of Mark.
- **The myth of the private schools** – a recurrent theme for justifying the rejection of a laptop was the perceived 'abuse' of the system by 'the private schools'. This shows a staggering lack of understanding of the application of the principle of equity. Even if evidence showed a systemic problem, the application of such a problem to specific cases is neither rational, nor based in evidence.
- **Lowest common denominator politics** – one complicating factor in the previous issue seems to be the assumptions made about over provision to private schools. The logic of reducing provisions across the board moves even further away from equity principles and advocates equity by lowest common denominator process. The idea of over provision is refuted below and it is suggested that it may be a convenient smoke screen for deficiencies in the public system.

Theme 3 Absence of provision of and consideration of evidence

One of the biggest concerns, in the experience of Mark and his family, was the lack of thorough consideration of evidence presented. More importantly, there seems to be no evidence basis for the provision of commonly provided alternatives such as the provision of scribes.

- **Of efficacy of provisions** – the BOSTES website provides no information on the evidence base for the common provision of scribes to students who request keyboard access. Best practice information on scribes suggests that BOSTES policy is entirely absent on such provision. Indeed, anecdotal evidence suggests that the use of scribes is highly variable. No training, standards or resources seem to be consistently applied. No account is taken of the requirement of students to practice under exam conditions many months out from their HSC exams, even though this is the explicit advice given to students.
- **Assumptions about assessment** – the rejection of Mark's original application without seeming to having read the details (this arose in conversation with BOSTES staff), not only raises issues about the limitation of rights of appeal, but also about the institutional confidence of BOSTES in its own policy requirements. This has implications for making correct decisions, but it also has implications for the considerable costs of assessment borne by the families of applicants.

Theme 4 What helped – the good and the lucky

In reviewing what helped the striking feature is that much is left to luck and circumstance. The details that follow, present some of the most pressing questions and ideas about what might be done to improve the experience of students with disabilities in attempting to represent their best capabilities and talents in HSC examinations.

- **Ethical, experienced professionals** – the ability to access highly regarded professionals in the assessment of Mark's condition and the articulation of his adjustment needs. Networks and resources play a significant part in this. The reputation of senior clinicians was a useful aspect to be able to draw on in making Mark's appeal.

- **Activist and advocate perspectives** – access to advocate/activist organisations – in particular for expert advice from advocates for gifted students with disabilities – was invaluable. The willingness of people involved in such activities played a large part in helping Mark achieve a fair and just outcome.
- **Privilege and status** – regrettably the ability to draw on resources and both positional and personal authority, seems to be a significant factor, not available to many parents of children needing disability adjustment provisions. Though there is no specific evidence that such things impacted on the appeal decision, it is the case that the appeal was made with implicit confidence and a clear indication that there were resources and intent to exhaust all possibilities beyond the appeal if needed.
- **Assertiveness** – despite a somewhat intimidating process, both Mark and his parents are lucky enough to have a strong capacity to assert their case and seek just outcomes. Mark's role as School Captain gave him credibility as a person who contributes to his school community and the confidence that comes with that. As an academic and senior public servant, Mark's parents have substantial intellect and rational capacity to assert their case. As with the above point, this is not true for all people and should have no bearing on achieving just outcomes.
- **Tenacity** – In addition to assertiveness and authority, the circumstances of this case were also such that barriers were more easily overcome due to the tenacity of Mark and his family. Disregarding the barriers and negative aspects is easier from a tenacious perspective, but tenacity in turn is fuelled by circumstances.
- **Capacity** – the above points indicate substantial wherewithal to take on a rigid system in this case. They inform much of the comment in section six.

5. Summary of the Case

Mark's application for disability adjustment provision for his HSC examinations was eventually successful. However the experience achieving success highlighted the substantial effort, resources and luck that students face in accessing appropriate provisions. The motivation to persist with his application was derived from a strong conviction that the request was entirely justified, evidence based and fair. The wherewithal to challenge a rigid and flawed system was a result of several factors, some of which are not at the disposal of all people with equally justifiable claims. The following section suggests some things that need to be done to make the system of disability adjustment for HSC fair for all students.

6. Things That Should Be Done

The following suggestions are listed below with a brief rationale as to their necessity.

Disability adjustment provision should be evidence based and consistent.

A recurrent theme of the experience in this case was the lack of attention to evidence. Despite the requirement to provide evidence, there were concerns that responses were generalised and based on common notions. The most alarming example was the idea that assessments by professionals were not thorough or reliable. Marks' assessment was rigorous and ethical – there was never a suggestion from the clinician that support would be given for adjustments that were not warranted.

On a similar note there seems to be a complete absence of consistent approaches to commonly proffered adjustments, such as policy on standards, training and resourcing of provisions such as scribes. Indeed mark's offer of a scribe was the selection of a support student from the school 'ambassadors list'. Mark himself is a member of this group.

Research should underpin systemic issues of access.

Common ideation regarding disability adjustment provision appears to have no research basis. It also seems that the wrong questions are put in relation to systemic issues. The strongest example of this is the common allegations that "private schools" play the system. Anecdotal feedback from clinicians seems to suggest that some private schools are simply engaged in better practice than their public counterparts.

A better question might be "what can we learn from this about best practice?"

More importantly, there seems to be no research on the apparent disconnect between the prevalence of disability in the general population and the lack of applications from schools in equal proportion. This would suggest that there might be many students needing provisions that are simply left out. The possibility that this might be more likely in vulnerable communities is a serious question that merits research.

Policy should match legislation.

The following point was made in Mark's appeal:

We respectfully submit these requests on the basis of what we feel to be fair and reasonable and in keeping with the provisions of the Disability Discrimination Act, as cited in the BOSTES website information.

This was just one example of practice appearing not to match disability legislation and policy. In particular the, often lauded, principle "nothing about us without us" seems to be at odds with practice. A better approach would be to ask people what works for them and then provide it, rather than a culture of deserving/non-deserving cases. There needs to be evidence to show that people are not reasonable in their requests before the assumption is made that they are 'playing the system'. There should not be a requirement to be 'grateful' for accessing fundamental rights and policy and practice should reflect this.

Getting into the current century.

In conversation with Mark's father the manager of the relevant BOSTES unit readily admitted that provision of keyboard access ought to be standard provision. The suggestion of use of a scribe for Mark was not only an inadequate response to his provision needs, it was also more costly and labour intensive. Disability provision

should be at the forefront of technological innovation. The technologies to do better, be more accurate in what they assess and environmentally more sustainable already exist and are tried and tested.

Training methods and culture

There is a need to put significant effort in to training of staff and people who assist student in disability provision. Anecdotal evidence suggests that this is very variable and relates to the possibility that some sectors do better. Standards, methodologies and cultural orientations to disability adjustment provision need to be developed through systematic professional development processes. Accreditation for supporter such as scribes would be a good start.

7. A final caveat

The intention of this case study is to provide phenomenological view of the experience of applying for disability adjustment provision, in order to shed light on some problematic issues. It is not meant to be critical of individuals. Mark has been a consistent champion for his school and speaks highly of his schoolteachers publicly and privately. He is a loyal member of his school community.

The issue for Mark and his family is that much of their success in achieving appropriate disability adjustment provision is based on attributes and resources that are not available to many. He will go into his HSC examinations in a fair context, where he can do his best. The problem is that he and his family have achieved that *despite* the systemic barriers. Some of these barriers seem easily fixed and should be. The presentation of this case is made on the basis of trying to help remove those barriers for all students.

Dr Mick Houlbrook, April 21, 2016