



Are We There Yet New Zealand?

IHC's Submission on Tomorrow's Schools Review



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IHC welcomes the report from the Independent Taskforce appointed to review Tomorrow's Schools. The review of Tomorrow's Schools is a central part of the major reform of the education system with the goal to establish a thirty year vision for education.

“We need a system – from cradle to grave – that is inclusive, that can adapt to the needs of the modern world. It needs to engage every learner – in a much more personalised learning experience.” Minister Chris Hipkins, February 2018.

IHC has engaged with the entire reform process and encouraged others to do so as we see the reform process as an unprecedented opportunity for the education rights of disabled students to be recognised and responded to in an education system where “every learner matters and matters equally.” (UNESCO, 2015)

Our 70-year history in advocating for the rights of children with intellectual disability to access education is well documented as are the difficulties faced by disabled students and their parents when attempting to secure learning opportunities at local primary and secondary schools. (Grant and Matthews, 2015)

IHC's position on inclusive education has developed over time and is strongly influenced by the voices of families and disabled people, our engagement with the education sector and research evidence.

A significant body of evidence was collected for IHC's legal action (a claim lodged under Part 1A of the Human Rights Act, 1993) in 2008 and 2014 and in additional surveys carried out in 2014 and 2017, receiving hundreds of responses each time.

There is no question that people want to have a say on how disabled students experience education and that they see IHC as a credible organisation to represent their interests and concerns.

In respect of this submission, IHC began an online

campaign towards the end of March 2019 surrounding the Tomorrow's Schools Review – with the aim of capturing real stories about what young New Zealanders with an intellectual disability were experiencing inside the classroom.

We created a website where people could submit their stories and opinions about what is being done well, and what should change within the current education system. We promoted five separate case studies through our social media pages, showcasing how children who required support to learn were able to succeed in the face of a broken system – that while luck and love worked for some, true change was needed to help the majority.

Within a week, almost 50 people contacted us directly to explain what they or their family members had experienced – ranging from parents to educational professionals.

These stories are included at the end of this submission and quotes from these are used throughout this submission. IHC's short-life campaign generated unexpected interest and activity, with a total of 6,517 engagements on Facebook, 465 shares, 3,999 total post clicks and a total reach of 59,158 people.

IHC's response to *Our Schooling Futures: Stronger Together* (henceforth referred to as the “the Report”) builds on IHC's long term advocacy and unequivocal commitment to inclusive education. IHC unreservedly supports and endorses the Education for All (EFA) submission prepared by Drs Jude MacArthur and Gill Rutherford.



1. IHC uses language derived from the social model of disability that acknowledges that people are disabled by a society that takes no account of people who have impairments and excludes them.

IHC welcomes the report from the Independent Taskforce appointed to review Tomorrow's Schools and supports many of the recommendations made. IHC's views on the content of the report and recommendations made are contained within this Report Card.

SUMMARY



EXCELLENT

"I have the hope that one day somebody with power, brain, and a good heart reads my words."

"We believe in public education. We were desperate to work within the system and hate that we have been forced out."

"Please don't make us fight for our children to have the future that they deserve. Please do not make us accept being a minority."

"He's a beautiful smart boy, who I feel the school is supportive, but their hands are tied to a certain point. I keep being told we are lucky to have a good school, but it should not be luck. The amount of time and energy and being 'vocal' to get what my other kids get naturally for my different boy is ridiculous. The system is beyond broken and it does need to be changed so all our children are included and get what they need."

"But I know he is intelligent and he has years of falling behind to catch up on. This experience, and my professional experience, make it clear to me that our education system is woefully under-resourced and broken. Children's rights to an education are not being met!"

IHC is in strong agreement with the overall findings from the Independent taskforce that:

- The education system is not working well enough for our most disadvantaged children and young people. This is not fair or just. Children from disadvantaged homes, too many Māori and Pasifika families, and those with significant additional learning needs remain the most poorly served by the system.
- The current system does not, and cannot, provide any assurance that we have capability or capacity to collectively improve outcomes for all of our children, particularly those in disadvantaged communities.
- Innovation and success are difficult to scale up because currently we have few mechanisms to enable system wide improvement to be initiated supported and sustained.

IHC strongly supports the recommendation that a cultural and structural transformation is required if we are to build a schooling system where all learners/akonga succeed.

The overall findings support and affirm IHC's long-held view that disabled students experience disadvantage and discrimination at school and that these problems are caused by the systems and structures of the Tomorrow's Schools model and the legislative and policy framework that supports and underpins it.

IHC notes and supports the Taskforce's overall findings that the self-governing school's model has not been successful in raising achievement or improving equity.

The overall findings and recommendations of the Independent Taskforce align almost entirely with the barriers identified and remedies sought within IHC's legal action under Part 1A of the Human Rights Act, alleging that disabled students experience unlawful discrimination at school.

The legal action attributes the problems and discrimination experienced by disabled students to inadequate, disconnected and incoherent systems and structures within the current education system.

1. GOVERNANCE



VERY GOOD

“In his third year, the Board of Trustees decided that they would not be topping up the TA time of any ORS funded students and that this was non-negotiable. These boards seem inherently opposed to the needs of disabled kids, in my opinion. You have a group of parents of neurotypical kids, presiding over funding decisions. When you ask whether they’d care to spend some money to make school possible for a “weird” kid and take it away from their own kids, for some reason they always say no. These people do not understand disability (especially autism). They are not trained educators, and yet they get to close the gate to education for disabled kids.”

“The school started suspending him from school when he had meltdowns. This included times when they would do things like take him to assembly (which we had explicitly warned them against because of the noise/social overload issue). The Board of Trustees declared that he would be treated like any other child and so would be suspended when he couldn’t cope and effectively would be subject to a three-strikes regime where after several suspensions he would be excluded altogether.”

“Of course funding is going to make a difference, but there also needs to be an attitude change for a lot of school communities first.”

IHC’s legal action identified that students with disabilities are often unfairly suspended or excluded for behaviours related to their disability, that parents felt that Boards of Trustees did not respond to complaints fairly due to a lack of understanding about education rights, disability and inclusive education, and that there is a lack of an advocacy service to raise concerns or complaints.

IHC supports the Report’s recommendation for the Education Hubs to provide a parent and student advocacy and complaints services, and take responsibility for processes when students are suspended.

We further recommend the establishment of an Independent Education Review Tribunal.

IHC also supports the recommendations that Boards of Trustees and Education Hubs represent the diversity of

their communities and recommend a requirement for all Board members and Hub personnel to evidence inclusive education knowledge and commitment, and in addition require representation of disabled persons along with Iwi representatives on school Boards of Trustees and Education Hubs.

IHC supports, in principle, the establishment of Education Hubs and cautions that further consideration is needed to ensure that the current difficulties that disadvantage disabled students relating to lack of visibility in school reporting and external monitoring, lack of early intervention to poorly performing and non-inclusive schools, lack of timely access to quality learning support provision, unhealthy school competition impacting on student enrolment are not replicated and embedded.

2. SCHOOLING PROVISION



VERY GOOD

“We should have taken a hint when they said that disabled kids couldn’t attend their open day.”

“Before he was allowed at that school, I tried to get him into another. Via an exception, nope. I tried enrolling my broken boy, ridden with anxiety with the kura, Ministry of Education says NO!”

“As a result, the only choice left to me was to put him back in the school where he was being beaten up, or home school him. All of this being my responsibility even though it’s the law to provide education and safety for students. I’m tired, I’m sad, I’ll now never own my own home and we will be a single income family for many years. I would love for my son to be given a place where he can learn and have what he needs to look after not only his education but his wellbeing.”

IHC seeks particular reassurance that safeguards will be firmly in place against magnet schools for disabled students given the proposed power of Hubs to control enrolment schemes.

Under the heading in this section ‘Different attitudes to support or students with additional learning needs can create magnet schools’ (p.60), there is the explanation:

“Some schools are more willing and able to meet the particular needs of a student than the school that happens to be the most close and convenient to that student’s home.”

IHC asserts that this wording is not only troubling, but appears to suggest that schools are able to refuse enrolment of a disabled child, thereby contravening the student’s legal right. Section 8 of the Education Act 1989 provides for students with

disabilities to have the same right to enrol at their local school as their non-disabled peers.

IHC’s legal action articulates that denial of enrolment on the basis of disability is unlawful discrimination.

IHC notes the recommendations for an expanded role for Te Kura but cautions that current high rates of enrolment of disabled students at Te Kura represents the failure of many schools to respond appropriately to the education rights of significant numbers of disabled students.

IHC supports the emphasis on well managed transitions between schools with particular attention placed on data transfer and access to supports and services.

3. COMPETITION AND CHOICE



VERY GOOD

“My child is only OK because we have the financial resources to be able to survive on one income, have a parent around for the kid, and pay private fees. I dread the thought of where we would be if we didn’t have these choices open to us.”

“I am the parent of an autistic 6-year-old girl. I definitely had the experience of being made to feel unwelcome when I contacted a couple of primary schools about enrolling (one private school). I ended up going with the school we were in the zone for because they were forced to take us on, fully prepared to home school if it fell apart.”

“The school that was open zone did not want him. Ten weeks. He was allowed in, but only because the Ministry of Education told them they had no legal rights to stop me. That principal also told me that in the five minutes she had met him she did not think he was this and that and he’d get no funding. Apparently her being a teacher overrides the medical professionals diagnosis, all because she did a few courses on it.”

“My daughter is autistic diagnosed at 7. She has been to seven schools in this time is now 15 years old. In this time, the two mainstream schools she attended she was bullied and her special needs insufficiently supported. I was told by one Principal that my daughter was manipulative! This is a child who has an intellectual disability, is autistic and has speech and language problems and sensory processing.”

IHC’s legal action included evidence that almost half of the families surveyed by IHC indicated that their child had been discouraged or denied enrolment at their local school. Over a third of school professionals surveyed were aware of denial and or discouragement of enrolments.

Denial of enrolment on the basis of disability is unlawful but is a well known practice that remains unchecked with few, if any, consequences for the school.

The rejection by schools and separation from siblings and neighbourhood friends embeds feelings of isolation, “otherness” and not being “OK” that are the antithesis to the child wellbeing government priority.

IHC supports the recommendations that each Education Hub has a planned network of state and integrated schools and has the oversight and direct responsibility for provision of schooling in its area.

We support Education Hubs having the responsibility to ensure that students with disability and learning support

needs have the same access as other students to their local schools and have a designated role to resolve any issues around enrolment.

IHC further supports the recommendation that current enrolment schemes be reviewed and adjusted as necessary to ensure they are fair and reasonable as part of the network planning and the need to consult with parents/whānau in balancing the needs of the network of schools and the provision of reasonable student and whānau choice.

The evidence collected for IHC’s legal action and responses to surveys carried out in 2014 and 2017, and the stories submitted to IHC’s 2019 social media campaign, identify that families/whānau receive financial requests from schools to supplement shortfalls in learning support funding.

IHC therefore supports the recommendation that in order to provide more equity in student and parent choice, there be an upper limit on the donations state schools can ask of parents. We also support the recommendation of consistent wording of requests for donations so that the voluntary nature is clear.

4. DISABILITY AND LEARNING SUPPORT



FAIL

“Kids that need TAs, even with ORS funding, do not get these fully funded by the Ministry. They make a “contribution” to the school’s TA costs. However, the schools are not required to top up TA time, and in our experience the Board of Trustees never want to. This leaves the student caught in a situation where they are entitled to an education, they need a TA to enable them to access and education, but no-one is actually responsible for making that happen, and the people who could make that happen are oriented to not fund that happening.”

“We applied for ORS, which was a terrible experience. I was forced to see ONLY my child’s deficiencies and shortcomings. My attitude towards who he was changed. We were initially denied funding despite him squarely fitting the criteria. One reason they gave me was that “you had to know that your child would not exceed level 1 of the curriculum by the time they left high school”. Well he was certainly on track for that without any support! What a dreadful system that uses that as a criteria to deny funding.”

The Disability and Learning Support section of the report fails to demonstrate an understanding of or commitment to inclusive education.

The recommendations in this section, despite the identification of a range of problems in recognising and responding to the education rights of disabled students, fall woefully short of the transformation promised – rather they demonstrate further tinkering of a flawed policy and resourcing framework.

IHC unreservedly endorses the submission made by the Education For All Forum (EFA) that promotes and profiles the need for an alternative approach to this section of the report and for the human rights approach articulated to be embedded in other areas of the report.

Remedies sought with IHC’s legal action to prevent the unlawful discrimination of disabled students include directing schools to collect data on a regular basis on the presence, participation and progress of disabled students requiring accommodations to learn and that this data is analysed and reviewed and reported to the Ministry for the purposes of monitoring school performance, individually and nationally.

In addition, one of the remedies sought within IHC’s legal action was the collection of robust prevalence data for the purposes of informing the national policy and resourcing framework.

IHC’s legal action identified that the current allocations and types of funding fail to respond to the actual numbers of students who require accommodations to learn and do not compare to international prevalence norms.

5. TEACHING



VERY GOOD

“The secondary school we chose had, and continues to have, a reputation of being inclusive of students with disabilities, but we experienced a lot of exclusion at the school. Whether she was included or not depended on her teachers. Some subjects and teachers would work hard to teach her and support her participation and learning. Other teachers would leave her education to teacher aides and basically ignore her. These teachers saw her and her education as the responsibility of the school learning support staff, and not themselves as the subject teacher. Twice teachers attempted to refuse to have her in their subject or classes, especially in senior years – we wouldn’t take no for an answer, but it backfired because the teachers didn’t want her there or know how to teach her, and so she would usually not get much out of that subject anyway.”

“I could never understand how a child could slip through a crack until I saw totally blank books come home. There was a huge crack he fell through.”

“Some of his teacher were great but others couldn’t be bothered with the extra demands of a child with ASD and didn’t know what to do, so would opt for exclusion as the easy option. Perhaps more training for teachers would improve teacher confidence and practice. I don’t think information about what worked for him and his assessments were communicated very well between teachers and from year to year.”

“I have been begging the school for more support, but as most teachers do not have any training my concerns and advice offers to help in class have been brushed off.”

“Teacher Aides need to be paid fairly. They need to be recognised for their great work, patience, tolerance, perseverance and the support they give to the classroom. They have no set curriculum, they work with what works with the child.”

IHC’s legal action identified through the collection of evidence from families/whānau and education sector professionals that initial teacher education and professional development did not result in teachers having capacity or confidence in teaching diverse learners. The legal action sought improvements in Graduating Teacher Standards and Teacher Registration to ensure that every teacher could demonstrate knowledge and competency in teaching the diversity of learners in all classrooms.

The Report confirms IHC’s position that teaching quality is variable and too many students feel marginalised by deficit thinking, unconscious bias and racism that evidence shows has lowered our expectations of success for particular groups of students for too long. Weaknesses identified were recruiting, training and supporting new teachers/kaiako, support for teachers/kaiako learning and roles, career pathways and support for paraprofessionals.

IHC strongly supports the Report recommendations for the development of a coherent future-focused workforce strategy

that includes a review of Initial Teacher Education to ensure it is fit for purpose. The emphasis on ensuring the diversity of teachers/kaiako more closely matches the student diversity is particularly welcomed as is the intention for viable pathways for paraprofessional development and employment at Education Hubs.

IHC also welcomes the Report recommendations focused on Education Hubs coordinating professional learning and development and advisory services, the development of professional learning groups across school networks and the links proposed between Education Hubs and the Curriculum, Learning, Assessment and Pedagogy unit at the Ministry of Education.

The recommendation for improved teacher appraisal options is supported, but questions remain about whether adjustments are required in Graduating Teacher Standards and Teacher Registration processes in regards to the demonstration of knowledge and capacity in teaching the diversity of learners in all classrooms.

6. SCHOOL LEADERSHIP



VERY GOOD

“We had regular Individual Education Plan (IEP) meetings with the school. The principal came to IEPs and was very interested in working creatively to solve problems.”

“He has been a victim of merciless bullying by his peers and teachers alike. Even beaten with a 4x2 by six students and the principal’s response was he would get worse on the rugby field.”

“I have been told his being bullied and abused is at every school and normal! And that if he did do XYZ he would not be targeted. By his first principal. After a year and a half of horror and my now then 6-year-old’s spark gone.”

IHC supports the Report recommendations to strengthen school leadership through a focused strategy with critical involvement of the Teaching Council and the Education Hubs. We support the systematic approach aimed at ensuring that all schools have the leadership they need and that the recommended changes to Boards of Trustees and Education Hubs would reduce the size and complexity of the principal/tumaki role so as to have a stronger focus on teaching and learning.

This area of the report could be strengthened by affirming that leadership at school, Education Hub and national level will be

critical to creating coherence and foster collaboration across reform efforts with an emphasis on providing a common, unifying understanding of equity and inclusion.

Evidence collected by IHC confirms the critical difference that school leaders make to the presence, participation and achievement of disabled students.

Recommendations recognise the need for increased ethnic representation however in school leadership roles but area is silent on the need for school leaders to be as diverse as the school population and community they are in.

7. RESOURCING



GOOD

“His teacher is amazing but has little to no resources to support him. I’ve had to start picking him up early because of the lack of support which means that I can’t go to work. This situation is financially stressful for our family. My husband works six days a week when he can so we can pay for everything we need including the extra therapies for my son.”

“We have finally managed to get 1.5 hours of Teacher Aide support on an interim basis split between our son and another ASD child. This isn’t good enough as there are several other kids in the class with special needs and behavioural problems.”

“But he is still not at school full time, he finishes at 1:50pm Monday to Thursday and has Fridays off school. This is how far his ORS funding stretches. I have been told the school has tried to get more funding, but haven’t been successful. There are other ORS kids and other kids with disabilities at the school, too.”

IHC welcomes the Report’s recommendations for increased investment in the education system, the proposed equity index (minimum of 6 per cent) to be implemented as soon as possible, that staffing entitlements and management resources be reviewed and that Education Hubs share practice on the use of equity funding and review school networks for quality education service provision.

Although the Report acknowledges the large increases in the number of children with additional complex behaviour

and learning needs and the increases in the number of children whose first language is not English the report recommendations are largely silent on additional resources required in the system to meet increased demand.

IHC regards this as a serious omission in this section of the report and recommends that data is gathered with urgency to inform a resourcing framework that responds to the actual numbers of students that require accommodations or support to be present, participate and achieve at school.

8. CENTRAL GOVERNMENT AGENCIES



VERY GOOD

“I know that there is an ongoing disconnect within the Ministry of Education that has led to learning disabilities being questioned and not recognised, and certainly not taught in teacher training. This is a Ministry problem and is appalling. The children and their families, and the enlightened teachers and administrators, deserve better.”

“To have now been excluded from all schooling because the previous principal and last principal refuse to accept the Ministry of Education’s help and advice to support our son in school, instead being told to find a ‘more appropriate’ school. But when asked, MOE told us he doesn’t qualify for special school he isn’t that severe. We are now in nothing land as MOE is saying correspondence is only a temporary thing, and trying to force us to a temporary residential school on other side of country but we keep saying other schools won’t have us because of these two principals until that changes we won’t be accepted – totally gutted and it’s having such a sad impact on our son.”

“The regional manager of the Ministry of Education and our daughter’s lead MOE person told us they couldn’t intervene because the school was a “self governing body”. They indicated that if she had been refused enrolment, they could act, but they could only encourage schools to change practices and remove barriers to participation, not require them to. We received the message from teachers, the principal, MOE and other families that we should be grateful that she was at the school and not to rock the boat and were made, to feel that we were unreasonable and demanding.”

Evidence collected by IHC over many years describes the long-held concerns and frustration with the lack of accountability within the schooling and wider education system and the lack of a mechanism to evaluate system performance.

The education rights disabled students and other groups of students not well served by the current education system have up until now not been well recognised or responded to individually or collectively nor has there been a pathway for system learning or innovation.

IHC therefore welcomes the recommendations to reconfigure the Ministry of Education, to create Education Hubs, to establish an independent Education Evaluation Office, to expand the role of the Teachers Council to include a leadership Centre and to disestablish the Education Review Office and the new Zealand Qualifications Authority.

Further safeguards are needed within the reform to ensure a vision for inclusive education is realised and a mechanism be established at the highest systems level to monitor the achievement of that vision.

SUMMARY OF KEY POINTS

1. IHC strongly agrees with the overall finding from the Independent Taskforce that;
 - a. “The education system is not working well enough for our most disadvantaged children and young people. This is not fair or just. Children from disadvantaged learning needs remain the most poorly served by the system.
 - b. “The current system does not, and cannot provide any assurance that we have capability or capacity to collectively improve outcomes for all of our children, particularly those in disadvantaged communities.
 - c. “Innovation and success are difficult to scale up because currently we have few mechanisms to enable system wide improvement to be initiated supported and sustained” (Our Schooling Futures: Stronger Together, 2019).
2. The problems expressed by IHC and others relating to disabled students being poorly served by the education system, the difficulties experienced with raising concerns from individuals or collectives and the low or lack of confidence that schools, the Ministry of Education or other parts of the education system can respond adequately or effectively – while increasing system capability and capacity – are now thankfully identified, confirmed and explained within the Report.
3. The problems associated with the wider education system not serving disabled students has been around for decades, pre-dating the beginning of Tomorrow’s Schools introduced under the Education Act 1989.
4. At that time, many members of IHC celebrated the fact that their sons and daughters would now be allowed to attend school (s.8 Education Act, 1989). Sadly, that early cheer was replaced over time with growing knowledge and frustration that having a legal right to attend on the same basis as their siblings did not mean their disabled child would be welcomed, given the supports to learn and achieve, make friends and participate in all of what school has to offer.
5. IHC welcomed the review of Tomorrow’s Schools wholeheartedly. There’s probably no greater example than parents who find themselves stuck between a school unable to fully accommodate their son or daughter, and an unwillingness of the Ministry of Education to do anything about it. For parents of disabled students, this is the reality of Tomorrow’s Schools.
6. In 2019, the difficulties are so entrenched and widespread that many parents, teachers and others from disability and education sectors have become inured to the reality, creating for many a sense that change is impossible.
7. The recommendations from the report of the Independent Taskforce signal a way forward that creates the possibility of not just change but of a cultural and structural transformation – building a schooling system where all our learners/akonga succeed.
8. IHC unreservedly supports this vision for change and many of the recommendations made. We particularly endorse the concerns for equity and goals for success for all students that permeate the entire report. IHC respectfully suggests that the report be strengthened with a greater acknowledgement and reference to the human rights of disabled students and contemporary understandings and research evidence on inclusive education.
9. The Education For All (EFA) submission, endorsed by IHC, offers a critique of Chapter 4, Disability and Learning Support: He Mahi Awhina I te Ako, and a re-imagining of the chapter from a contemporary, evidence-based viewpoint. We agree with the suggestion that making good decisions about our schools and ALL students is reliant on a shared understanding about what inclusion means and why it is important (Ainscow & Messiou, 2018; Slee, 2018).
10. IHC’s legal action under part 1A of the Human Rights Act¹ alleges that disabled students experience unlawful discrimination at school and that the discrimination is related to the systems and structures of government. Significant amounts of evidence were collected detailing the different treatment disabled children were experiencing in matters to do with enrolment, accessing the curriculum and participating in school life. The second amended Statement of Claim was lodged with the Human Rights Tribunal in August 2014. A preliminary hearing was held in 2015 and now some four-and-a-half years later IHC still does not have a date for the substantive issues to be heard.
11. The barriers or difficulties identified in IHC’s legal action that created problems for individual disabled students were inadequate initial teacher education and professional development, the special education (now known as Learning Support) policy and resourcing framework, a lack of sound prevalence data, inadequate monitoring, reporting and accountability and school decision-making in regards to suspensions and exclusions.
12. IHC therefore supports the attention given to these areas within the Report and makes comment on the recommendations for change. It appears that even without a hearing in the Human Rights Review Tribunal IHC’s identification of the systemic weaknesses and the problems they create have been confirmed.

1. Second Amended Statement of Claim dated 18 August 2014, IHC v Attorney General, in the Human Rights Review Tribunal HRRT024/2012

As stated previously, IHC welcomes the government's commitment to education reform and notes the complexity and range of the work being progressed. Given this unprecedented opportunity to develop a quality public education system that engages and ensures success for every learner, it will be important to "get it right".

The following headings highlight areas IHC believes warrant further consideration and/or reassurance. We note, and endorse, the points made within the submission from Education For All (EFA) – some of which are replicated and/or expanded on in the following discussion points.

Quotes at the beginning of each section are from families and education professionals who provided stories to IHC's social media campaign #AreWeThereYetNZ.

Integrated Education Reform

"We do not need changes, we need a complete rethink."

"My son had no business being in a mainstream school without the right support and education for those around him."

"Even with a new system in place, if it can't be funded then it will also fail."

"They are us. They are ours."

All aspects of the education reform being progressed are critical to disabled students.

IHC notes, however, that it is difficult to see how the interests and rights of disabled students are visible within, and across all of the reform work streams. Although the Disability and Learning Support work programme is identified as one of the reform work streams, IHC asserts that it is of fundamental importance that clear links are made to the other reform work streams. A segregated approach to disabled students interests and education rights is clearly not the intent of the education reform being progressed.

The February 2018 statement from Education Minister Chris Hipkins, "We need a system from cradle to the grave - that is inclusive..." understandably raised expectations that the quality public education system to be developed will be one where every learner is included and successful.

The strong recommendation from the Independent Taskforce appointed to review Tomorrow's Schools, that a cultural and structural transformation of the education system is needed so that equitable access to, through and from education is assured for all students, affirms the inclusive approach being taken with the reform.

IHC is concerned, however, about the lack of an integrated reform work programme that has visible linkages between each area of work and where disabled students are visible within each work stream. For those outside of government, it is impossible to monitor how the interests of groups of children are being recognised, and responded to, within and across the various reform work streams and also what mechanisms or structures exist to ensure an integrated approach is being taken.

An integrated approach is critical to transformation. The EFA submission rightly points to the guidance found within Roger Slee's (2018) recent think piece prepared for UNESCO and the 2020 Global Education Monitoring Report. In his report, Slee poses the following questions that are integral to the transformation of our education system towards inclusion:

- What kind of world do we want our children and young people to live in?
- What kind of schools and classrooms are required to achieve that world?
- When we look at our schools – who is in, who is out, who decides and what are we going to do about it? (Slee, 2018, p. 9).

Recommendation

Education reform leaders clarify the linkages between the Disability and Learning Support work programme being progressed to the overall work and progress being made in all other reform work streams and the visibility of disabled students within them.

Inclusive Education

“Despite the school having good intentions, he was unsupported and vulnerable. Before arriving in New Zealand my child’s life looked just like his siblings – full and happy with achievements.”

“One reason they gave me was that ‘you had to know that your child would not exceed level 1 of the curriculum by the time they left high school.’ Well he was certainly on track for that without any support! What a dreadful system that uses that as a criteria to deny funding.”

“This year has been absolute hell due to him having no support and no communication that his teacher aide from last year had left. Since school started back my son has become violent, manic and suicidal.”

“I had an 8-year-old girl chat with me last week. Telling me ‘just because he is different, does not give the kids and teachers the right to treat him badly’ – she follows on to say ‘you know they bully him and are not nice to him aye? Just because he does things differently.’”

“Of course funding is going to make a difference, but there also needs to be an attitude change for a lot of school communities first”.

IHC shares the view of the Human Rights Commission that the Report demonstrates there is not a shared understanding of, and unequivocal commitment to, inclusive education.

IHC is also in agreement with the EFA submission (p.8) that a clear rights-based definition of inclusive education is needed to ensure a shared understanding among all involved in determining and enacting the proposed reforms, as well as those who will be affected by the latter.

The lack of a clear rights-based definition of inclusive education is a serious matter, as is the Report’s recommendation, that “special schools are a vital part of the schooling system” (p.79) given the government’s obligations under Article 24 of the United Nations Committee on the Rights of Persons with Disabilities and the New Zealand Disability Strategy.

New Zealand has been criticised on the international stage for denying disabled children’s rights to an inclusive education and breaching Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) (Grant & Matthews, 2016; Independent Monitoring Mechanism of the CRPD, 2016; Moran, 2014).



As discussed earlier in this submission, widespread concern relating to the lack of a quality public inclusive education system is well known and documented, as is the discrimination disabled students experience accessing enrolment, the curriculum and participating in school life on the same basis as their non-disabled peers (Second Amended Statement of Claim, IHC v Attorney General, 2014).

The Report appropriately acknowledges and affirms Te Tiriti O Waitangi in the proposed reform and the critical importance of a kaupapa Māori approach in education policy and practice and need for monitoring and accountability at the highest systems level.

IHC recommends that further safeguards are needed within the reform to ensure a vision for inclusive education is realised and a mechanism be established at the highest systems level to monitor the achievement of that vision.

Inclusive education is a human right. IHC strongly endorses the views expressed in Education for All submission that;

Inclusive education means every person, social, and cultural group experiences a quality, inclusive education and that all students experience lifelong benefits of participating, succeeding and achieving in an education system that actively values their identity (Education For All, 2018). In order for the existing recommendations to lead to the

transformative changes indicated in the report, we urge the Taskforce to reconsider what equity and inclusion means and looks like in practice for disabled children and young people, their families and whānau, teachers and the wider community. Such a reconsideration needs to be informed by a human rights and evidence base that includes students', educators', whānau, policy makers' and researchers' (particularly New Zealand researchers) ways of knowing and thinking, and the Treaty, human rights conventions and New Zealand policies listed above (p.6 Education For All, 2019).

Every day, barriers to inclusive education in New Zealand are evident – lack of understanding of what inclusion really is (as distinct from integration or mainstreaming), lack of appreciation of the benefits of a system that welcomes diversity and difference and, of course, a lack of resources. The resource issue is not just about supporting students with a disability fairly, but also providing accessible buildings, adaptive technologies and relevant curriculum materials. Speakers affirmed that the absence of these essential supports, which allow a disabled child to access education, was discrimination. We heard from UN Committees on children's and women's rights. The speaker representing the Rights of the Child challenged those present to see that a denial of the right to an inclusive education was in fact "abusive" (Grant & Matthews, 2015).

The Human Rights Act 1993 protects New Zealanders of all ages from unlawful discrimination. IHC's claim under Part 1A of this Act, arguing that disabled students experience discrimination at school, is still to have a full hearing despite being lodged with the Human Rights Review Tribunal more than four years ago.

Given this, in the knowledge that disabled students' human rights to inclusive education continue to be breached and given that their human rights to be protected from discrimination at school are yet to be considered, and having exhausted all domestic remedies, IHC is considering taking action on behalf of disabled students and their families under the Optional Protocol established under the UNCRPD.

Recommendation

IHC recommends that:

- a clear rights based definition of inclusive education is included in the Report
- further safeguards are needed within the reform to ensure a vision for inclusive education is realised and a mechanism be established at the highest systems level to

monitor the achievement of that vision.

- the Taskforce reconsider what equity and inclusion means and looks like in practice for disabled children and young people, their families and whānau, teachers and the wider community and that the reconsideration is informed by a human rights and evidence base that includes students', educators', whānau, policy makers' and researchers' (particularly New Zealand researchers') ways of knowing and thinking, and the Treaty, human rights Conventions and New Zealand policies (p.6 Education for All Submission 2019).

Education Law and Policy

"The regional manager of the Ministry of Education and our daughter's lead MOE person told us they couldn't intervene because the school was a 'self-governing body.'"

"The Education Act states inclusion, and unfortunately this couldn't be further from the truth."

"Children's rights to an education are not being met."

The Report is silent on the legislative and policy underpinnings for inclusive education.

New Zealand's obligations under Article 24 of the UNCRPD in respect of disabled students' rights at school include;

The right to access an inclusive, quality education on an equal basis with others [Art 24(2)(b)].

Reasonable accommodation of the student's requirements [Art 24(2)(c)].

The right of students to receive support within the general education system, and that such support measures are effective, individualised, provided in environment that maximises academic and social development, and consistent with the goal of full inclusion [Arts 24(2)(d) and (e)].

Compliance with Article 24 requires a legislative commitment. In the General Comment on the Right to Inclusive Education under Article 24, the UNCRPD Committee states that:

"The right to inclusive education encompasses a transformation in culture, policy and practice in all formal and informal educational environments to accommodate the differing requirements and identities of individual students, together with a commitment to remove the barriers that impede that possibility... It requires an in-depth transformation



of education systems in legislation, policy, and the mechanisms for financing, administration, design, delivery and monitoring of education” (Article 24 UNCRPD General Comment).

Monitoring of New Zealand’s compliance with the UNCRPD has led to a call for the right to inclusive education to be included in the Education Act as the means to achieving full implementation of Article 24. In its 2014 review of New Zealand, the UNCRPD Committee concurred with the Independent Monitoring Mechanism’s position that the Government establish an enforceable right to inclusive education within legislation.

Recommendation

IHC recommends that an enforceable right to inclusive primary and secondary education is enacted along with the right for disabled students to receive reasonable support and assistance necessary to accommodate their individual education needs.

Accountability

“Does the Ministry of Education know that with a good intervention, the progress of a human being with disabilities can improve? Around a special needs boy or girl, there are ‘normal students’ that are learning how the authorities are being so unfair, they are learning that there are children better than others and they don’t deserve an education.”

“He basically spent his high school years at home.”

“It took a very long time and a letter to the Minister of Education and Prime Minister to finally get support in day care. The journey to primary school was a rollercoaster.”

“Education should not be a battle. Parents should not have to fight or just accept mediocre support or responses. Writing to the Prime Minister should not be what it takes to get support for your child.”

IHC endorses the recommendation made in the Education for All (EFA) submission that inequities in education for disabled students must be addressed through effective monitoring and accountability mechanisms that document experiences of exclusion and inclusion in and from education (Slee, 2018). The Report emphasises the need for accountability in education in relation to our responsibilities to Te Tiriti o Waitangi and to the learning and success of Māori students. Similarly, reforms will, and must, be concerned with accountability in regard to the quality of disabled students' learning and social experiences at school. At the most fundamental level, disabled students' rights to an inclusive education are undermined when schools suggest that their 'special needs' will be better met elsewhere (Wills, Morton, McLean, Stephenson, & Slee, 2014). Reforms will therefore include the incorporation of both a clear definition of inclusive education and the enforceable right to inclusive education into the Education Act 1989.

The Report recommends that the proposed Education Hubs be responsible for many of the 'business' and governance duties currently held by school boards while also providing specialist educational support to build good teaching and learning. Education Hubs are to support schools individually as well as collectively by partnering with and monitoring schools on a collective basis to ensure they are supported, and any problems are identified and responded to early.

IHC welcomes the Report's recommendations to establish Education Hubs and the links with Kāhui Ako and supports the views expressed within the EFA submission that these are useful structures for supporting collaborative, middle management solutions and local developments that will advance inclusive teaching practice and the reform agenda more broadly.

Many of the stories attached to IHC's submission identify the current tensions between schools and the Ministry of Education and the barrier that this creates in having a 'systems' response to resolving problems. The stories also reference the current and persistent difficulties in accessing learning support provision from the Ministry of Education.

IHC is therefore concerned about where accountability sits in resolving these long term problematic areas and how the Education Hubs will demonstrate strengthened accountability to disabled students and their families/whānau. We welcome the proposal that the Education Hubs provide parent and student advocacy and complaints services and take on the responsibility for processes when students are suspended.

Recommendation

IHC recommends that accountability in the areas above require strengthening and recommends that;

- that Education Hubs demonstrate effectiveness and accountability in resolving problems and ensuring that learning support provision responds to the actual need in the areas the Education Hubs serve
- An Independent Education Review Tribunal is established to ensure that decisions made about students are subject to external from the education system scrutiny.

Language and Identity

"The special needs unit is a return to the '80s. Firstly, it is set in the middle of the high school with huge signage saying 'special needs unit.'"

"Our high school is so proud that they provide/'give' a building to these kids right in the center of their grounds. But that is where the relationship stops."

"They basically just keep the kids busy – some basic learning coupled with collecting pine cones and doing work experience in menial jobs, sorting rubbish at Salvation Army, emptying seedling containers at a local nursery. The kind of thing that will prepare kids to be a low-achieving member of society."

"When we moved, the school refused to see him after they read his reports. He has no behavioural issues and brings joy to so many people of all ages. He contributes to verbal discussions in class and often makes valid points. He has a memory like an elephant. He has a lot to offer."

The Report accurately names the problems disabled students experience to do with being welcomed, accessing the curriculum and participating in school life. The difficulties with getting the right support at the right time are well described, as is the reality for disabled students that they do not have the same access to schooling as other students.

There are significant problems, however, in the language used in this section of the Report.

In addition, IHC strongly rejects the approach taken within Disability and Learning Support chapter of the Report and asserts that it does not demonstrate transformation of existing arrangements rather a further 'tinkering' of the broken system that has significantly disadvantaged disabled students for too long.



“Multiple reviews and reports over several years have shown the education system is not working for disabled students. Significant outstanding issues for the system include under-resourcing, a lack of good accountability mechanisms, lack of data and options and a lack of training and support for teachers. We’ve known this for a long while; New Zealand just has not addressed these issues meaningfully and comprehensively”

(Paula Tesoreiro, Disability Human Rights Commissioner as quoted in Good Connections for Valued Lives, IHC 2019)

The Report summary of the chapter states that the Ministry of Education’s new Learning Support delivery model and the draft Disability and Learning Support Action Plan will ‘hopefully’ (emphasis added) provide much needed coherence and increased funding and accessibility ‘for these students and their parents’ (emphasis added).

IHC respectfully suggests that disabled students and their parents need, and have, a right to more than a ‘hopeful’ approach – that they need certainty that, at last, there will be an end to the problems they endure.

As one parent has described to IHC, “Our cup is overflowing with love for our Taonga, but we are exhausted.

“Please don’t make us fight for our children to have the future that they deserve. Please do not make us accept

being a minority. Please let our kids be educated the way they need to be with the best resources and support. Please listen to us because we are exhausted.

“They are children who should make it through University, into the workforce, travel the world, get married and have a family.

“Treasure our Taonga. Give them equal opportunities. Let them receive adequate education and give their teachers the right tools and wrap around support to have a positive impact on the entire classroom. Support their Principals and fellow pupils.

They are us. They are ours.

IHC strongly agrees with the views expressed about language within the EFA submission;

A review of language is necessary, given that terms such as ‘special’, ‘specialist’, ‘additional needs’, ‘challenges’ (both within children and that children cause for schools), default to a deficit/ adjunct/add-on mentality in relation to disabled students, which obscures recognition of and undermines students’ rights. The label ‘special education’ fails to recognise the influence of ecological and social contexts on children’s learning and social experiences at school, and gives people permission to use discriminatory practices (Smith, 2013). Critiquing and contesting entrenched ‘special needs-ism’ is essential if we are to achieve a genuinely inclusive education system for ALL students (Rutherford, 2016). Replacing ‘special educational needs’ with ‘educational rights’ means that all students are valued and their identities are upheld (MacArthur & Rutherford, 2016; Runswick-Cole & Hodge, 2009; Slee, 2018). We have used the language of ‘learning support’ in this chapter, however there is an opportunity to critique the ideas that may sit behind the use of such terminology, particularly when it is only applied to disabled students and the staff who are designated as being responsible for ‘working with’ students. Used in this specific way, there is a risk that disabled students will be viewed as in need of ‘help’, as always dependent on adult support, and ‘additional’ approaches, resources, ways of teaching. Equally, an entire infrastructure of adult ‘support’ is built around the child which aims to support them and lift their performance, rather than focusing attention and efforts on developing the context in which students learn so that all students can fully participate, learn well and have friends. In this regard we suggest a change away from the language and ideas of ‘learning support’ to the many ways in which teachers and other staff can ‘work with’ a diverse student group.



Recommendation

IHC endorses the recommendation made within the EFA submission that:

- All levels of the education system, from policy through to practice, that ideas and language in the reforms reflect disabled people's rights as equal citizens and students at school, and reject the binary "special/regular".
- Reforms would involve a transformation of the conceptualisation, structures, protocols and practices of both 'regular' and 'special' education based on inclusive education and human rights.
- Terms such as 'special', 'specialist', 'additional needs', 'challenges' that default to a deficit/ adjunct/add-on mentality in relation to disabled students would be replaced with language and ideas based on 'educational rights' so that all students are valued as equal citizens and their identities are upheld.
- Schools and learning programmes must become accessible for all children – including children with disabilities. Reforms, including associated policies, structures, systems and professional positions relating to learning support, would focus on developing the context in which children and young people learn – schools would change to respond positively to student diversity, including disability.

Conclusion and Recommendations

IHC welcomes the opportunity to provide feedback on the report from the Independent Taskforce established to review Tomorrow's Schools.

IHC unreservedly supports the summary recommendation that a cultural and structural transformation of the education system is needed so that equitable access to, through and from education is assured for all students.

IHC makes the following recommendations to strengthen the Report:

- The education reform leaders clarify the linkages between the Disability and Learning Support work programme being progressed to the overall work and progress being made in all other reform work streams and the visibility of disabled students within them
- A clear rights-based definition of inclusive education is included in the Report
- Further safeguards are established within the reform to ensure a vision for inclusive education is realised through a mechanism at the highest systems level to monitor the achievement of that vision
- The Taskforce reconsider what equity and inclusion means and looks like in practice for disabled children and young people, their families and whānau, teachers and the wider community and that the reconsideration is informed by a human rights and evidence base that includes students', educators', whānau, policy makers' and researchers' (particularly New Zealand researchers) ways of knowing and thinking, and the Treaty, human rights Conventions and New Zealand policies (p.6 Education for All Submission 2019).
- IHC recommends that an enforceable right to inclusive primary and secondary education is enacted along with the right for disabled students to receive reasonable support and assistance necessary to accommodate their individual education needs.
- That Education Hubs demonstrate effectiveness and accountability in resolving problems and ensuring that learning support provision responds to the actual need in the areas the Education Hubs serve
- An Independent Education Review Tribunal is established to ensure that decisions made about students are subject to external from the education system scrutiny
- All levels of the education system, from policy through to practice, that ideas and language in the reforms reflect disabled people's rights as equal citizens and students at school, and reject the binary "special/regular".
 - ◊ Reforms would involve a transformation of the conceptualisation, structures, protocols and practices of both 'regular' and 'special' education based on inclusive education and human rights.
 - ◊ Terms such as 'special', 'specialist', 'additional needs', 'challenges' that default to a deficit/ adjunct/add-on mentality in relation to disabled students would be replaced with language and ideas based on 'educational rights' so that all students are valued as equal citizens and their identities are upheld.
 - ◊ Schools and learning programmes must become accessible for all children, including children with disabilities. Reforms, including associated policies, structures, systems and professional positions relating to learning support, would focus on developing the context in which children and young people learn – schools would change to respond positively to student diversity, including disability.

CASE STUDIES

Towards the end of March, IHC began an online campaign surrounding the Tomorrow's Schools Review – with the aim of capturing real stories about what young New Zealanders with an intellectual disability were experiencing inside the classroom.

We promoted five separate case studies through our social media pages, showcasing how children who required learning support were able to succeed in the face of a broken system – that while luck and love worked for some, true change was needed to help the majority.

Within a week, almost 50 people contacted us directly to explain what they or their family members had experienced – ranging from parents to educational professionals.

These are their stories.

Max and Antonia: Belonging

“We need more than integration, we need real inclusion.”

Max started his educational career at a special school, but wanted to go to mainstream. The family found a non-zoned primary near their Auckland home that offered them the belonging Max craved, says his mum, Antonia.

“Max requires some understanding about how he interacts with the world. He’s a great example of someone with reasonably complex needs in the system. We needed a school that would support Max to achieve his own version of success rather than forcing him to conform, a school that would support his right to be there, and appreciation that poor behaviour can be the result of feeling like you don’t belong. We needed a school prepared to include Max with a ‘whole school’ approach to learning support.

When Max started at mainstream I was invited into class to talk to the children. It laid the groundwork by helping them put themselves in Max’s shoes. I also spent time working with the teacher – at their request – educating them about Max’s disability. The teacher used that information to develop a good relationship with Max.

The school quickly realised that if Max didn’t follow the rules it wasn’t necessarily ‘naughty’ behaviour but a need not being met. The school was careful to keep rules simple and when rules were broken to ask ‘why’? He kept using the junior playground instead of the senior one, and instead of telling him off the school asked ‘why’? It turned out the equipment in the senior play area was too complicated for Max, so they addressed it, facilitating him to join in with his peers.

Teachers accepted some of Max’s more out-of-the-box behaviour, and warded off concerns from other parents with positivity and enthusiasm for Max’s role in the school.



With support from staff we created an inclusion network to better meet the needs of pupils with disabilities and learning differences. They also secured extra funding for programmes like music therapy, and created a new format for school reports to celebrate the successes of children like Max.

Max has been advocated for by his school from the start and included in every activity from camp to performances. He’s valued by friends and teachers, has learned well at his own level, and become a happier person. I’d love to see all schools including their children who need learning support in this way.”

Lucas and Stephen: Home Schooling

“We’re not hippy rejects, we home school because there was no other option.”

Some families in New Zealand choose to home school for philosophical reasons, but many others are home schooling because the education system cannot support them. There are no accurate statistics around this, and it needs to change, says Stephen, dad to Lucas, eight.

“At kindy, Lucas was a happy and relaxed child with good friends. He wasn’t developing as fast as his peers, but he was curious and loved tactile, play-based learning so we weren’t worried. He was just going at his own speed.”

He started school at five and immediately struggled with the highly structured environment. Instead of being supported to learn at his own pace, the school reported back that he wasn’t meeting expectations. Unable to keep up with the class, he disengaged from learning and was considered disruptive.

The school felt he must be ASD or ADHD, and they pushed us to seek a diagnosis. They provided a speech therapist and some support with handwriting, but they told us without a formal diagnosis they couldn’t do more. However, a paediatrician confirmed there was no diagnosis to be had, he was just developing more slowly. He began to be left to his own devices at school, he felt stigmatised, lonely and dejected.

“I was quite against home school, but we couldn’t see any future at school either. We pulled him out and after a few months of loving care we started to see our happy-go-lucky little boy back again. My wife Pauline and I provide him with good structure and variety at home, and while I don’t think he will be a rocket scientist, everyone has a little place in the



world and Lucas will find his.

“Home school has been a good decision for us, but we didn’t end up here by choice. We aren’t trouble makers or hippy rejects, the system just wasn’t able to support Lucas – and there are thousands of families like us. There are so few stats around home schoolers; how many are there because the system doesn’t work for them? How many go to university? Why does home school work? Understanding this is key to getting better support in schools, and hopefully better support for those of us home schooling as well.”



Mark Potter: Funding

“Funding learning support is a matter of priorities.”

Berhampore School in Wellington has prioritised learning support in a way that demonstrates how a well-funded system could support all children to success, says principal Mark Potter.

“The current system is financially deficient. For example, we have five Ongoing Resourcing Scheme (ORS) funded students, but as a school we still need to find \$8,000 per student per year so they can access meaningful education. We do this by making

learning support a priority, and that means we have to let other things go, like building maintenance. We put the children at the centre.

Our philosophy is based around the child’s right to be here. Berhampore School is everyone’s school – we don’t turn people away. Instead, we ask what accommodations do we need to make so this child can access school like their peers?

We employ 16 teacher aides because we believe a classroom teacher alone cannot support children with communication and behaviour challenges and still meet the needs of the whole class. We fund our own learning support coordinator (LSC) to take the admin load off the teachers. When a child has a meltdown it is often the LSC or me that deals with it so the class can continue. The LSC also develops a team around each child with a need, even if it’s not formally diagnosed or funded. The team always includes the parents – family communication is key. I support the idea of LSCs but one who can get to know the community, not ‘drive by experts’ with no connection to the school or the children.

Perhaps the biggest difference is the way we measure success. For some children it could be using the toilet independently or making a genuine friend in the playground. There are so many different ways of looking at success, and each child is supported to succeed in their own way. The way we resource children to achieve is flexible to the goals, not just academically focussed.

The Tomorrow’s Schools review has some key concepts underlying it that will enable change, but it is lacking in financial resourcing. We can’t keep reducing money in comparison to what we need that money to do. We need a clearer idea of the need, and we need to fund it appropriately.”

Maryann Hainsworth: Professional Development

“Teacher aides need to be trained to be effective.”

The role of teacher aide is de-centralised, de-professionalised, low paid and legally requires no training or experience, but Lower Hutt based TA Maryann Hainsworth says she couldn't do her job without specialist vocational knowledge.

“I was a parent helper in class for all five of my children, a long time ago now. One of the things I noticed was that many of my children's friends who were all bright and engaged at Kindy struggled in mainstream education. I thought to myself, ‘these kids should be doing well, why aren't they?’ Later they were diagnosed with special educational needs, like dyslexia, and I felt driven to help.

I applied for a role as a TA at a nearby school 14 years ago, but before I did that I completed a Teacher Aide Postgraduate Certificate at Open Polytech. I didn't have to, but I felt I needed to. Even with my experience volunteering in school, I needed to know things like what the reading levels meant, clues as to when a child was falling behind, and strategies to help them learn when the usual techniques weren't working.

I've completed courses in Feuerstein method and behavioural needs, literacy, numeracy, including numicon and development of motor skills. Some courses the school have paid for, some NZEI have provided a scholarship for, and some I've paid for myself. Occasionally, there has been a course aimed at teachers and I've managed to slip in. I'm quite proactive in finding courses, but even so my professional development has been patchy. Every TA should have a clear career pathway to develop and progress. These additional courses and supports have made me more



confident, given me tools and skills and helped me develop a network of professionals with similar experiences to trouble shoot with.

I don't believe a TA can do their job without any training. They come in and they get on with it, but they can't do it as well as someone who has had training. It's the same as any job – I couldn't go in and use a till in a shop for example, I wouldn't know how. We are dealing with some of the most vulnerable human beings – there has to be training on how to support them to succeed.



Felix and Kerry: Wellbeing

“We need to recognise how essential emotional wellbeing is to good learning, and facilitate it for all children from the start.”

Much of the current support offered to learning support pupils is focussed on academic achievement, but good emotional health and wellbeing is vital for students to be raised to their version of success, says Kerry, mum to Felix, 9.

“Felix wants to be at school, but struggles to be there as

well. The classroom is noisy, he feels overstimulated, or he experiences anxiety and runs away. This is obviously disruptive for the class, and dangerous for Felix.

We've had Intensive Wraparound Service funding for a year, and it was hard won. We had a bumpy start but once early issues were ironed out, we've seen a huge improvement in Felix's ability to engage in school, and the joy he feels at being there.

The main points for Felix to work on are emotional regulation and social skills. Monday and Tuesday he is supported full time by a teacher aide. Wednesday and Thursday he is supported until 1pm and then leaves school. Fridays, he works alongside a specialist teacher. We've also got support from an occupational therapist and we are applying the techniques at home. It's been fantastic.

Felix is starting to understand his emotional responses. If he does feel the need to run, he can identify and acknowledge why. And he is learning strategies to deal with his emotions too, both at home and at school. We were introduced to the Zones of Regulation Programme – it's not only helped Felix with understanding his emotions, but our neurotypical child too. Every child needs to learn this in my opinion.

The ultimate goal is for Felix to be able to self-regulate at school full time. When the funding ends this year there will be limited support for him. If every classroom had a fully trained teacher aide to support the work of the teacher, Felix may not need specialised help. At the moment our system is the ambulance at the bottom of the cliff. We know there is a problem, the current system isn't supporting our neuro-diverse kids, but services aren't put in place until it's almost too late.

PARENTS & FAMILY/WHĀNAU

Noah*

Our youngest, Noah, child has Autism (ASD), ADHD and a diagnosis of Pathological Demand Avoidance (PDA). His ASD manifests in sensory disorder - he is hyper sensitive to noise and to a lesser degree, visual clutter. He doesn't understand social situations and he has poor fine motor control. PDA is not officially recognised in NZ but is accepted in the UK. Put in its simplest form, the PDA diagnosis expresses the idea that Noah's disability is mainly about anxiety and difficulty dealing with social situations. This is probably quite important to note since a lot of the supports for kids with disabilities seem to be premised on either physical disability or intellectual disability that lowers IQ. There doesn't seem to be much recognition of kids who are perfectly intelligent but who can't manage to be in a class due to being overwhelmed either socially or from sensory overload.

Noah qualified for high needs ORS funding and so was entitled to 18hrs TA time when he was at school and 2.5hrs specialist teacher time per week.

Primary School - we had a TA to help Noah in class. We had regular IEP meetings with the school. The school sent some of their staff on Autism training. We got the feeling that - at least at the outset - the school were very interested in trying to do well for Noah.

The room that Noah was put into was very cluttered and noisy. We mentioned that this wouldn't work well for Noah but it was not something the school could or were willing to change in any way. Noah ended up having regular meltdowns due to sensory overload/anxiety.

Noah had a time-out room that was intended to give Noah space to calm down after a melt down or a quiet place to work when he needed quiet. We told the school that this should not be used as a punishment for Noah being agitated in class, but it increasingly became one, and his school time ended up being largely him in the time out room.

One of the really clever things that was sorted out for Noah was recognising that using a computer with predictive text would make him very productive with his writing (given that he struggled to write by hand and was happy using computers). The Ministry supplied a computer for Noah to use for that purpose.

There was constant pressure from the Ministry for the school to reduce its funded TA time. The Ministry appeared to be concerned with minimising TA costs. The school seemed to be concerned with not spending anything on TAs - while also recognising that TAs were hugely important for these kids. There's an obvious gap here. Kids that need TAs, even with ORS funding, do not get these fully funded by the Ministry. They make a "contribution" to the school's TA costs. However, the schools are not required to top up TA time and in our experience the Board of Trustees never want to. This leaves the student caught in a situation where they are entitled to an education, they need a TA to enable them to access and education, but no-one is actually responsible for making that

happen and the people who could make that happen are oriented to not fund that happening.

The TA helps Noah by being someone to help keep him emotionally balanced in order to be able to remain in class. They see when he is overloaded and pull him out of class to wind down and bring him back when he is capable. He can get through a day of work when this happens. He has meltdowns when he gets overloaded. He had no ability to monitor or manage his own stress load.

Noah had a large chunk of one-off funding from the Ministry that the school could use for improvements. Noah was a flight risk - he would run away from school. So the school got well over \$100,000 from the Ministry to improve their fencing. They also funded to put a new door on the room Noah was using for time-out and added an adjoining sand pit and decking. When the work was done, they decided to use the room for a class and that Sam couldn't use it.

In his third year, the Board of Trustees decided that they would not be topping up the TA time of any ORS funded students and that this was non-negotiable. These boards seem inherently opposed to the needs of disabled kids, in my opinion. You have a group of parents of neurotypical kids, presiding over funding decisions. When you ask whether they'd care to spend some money to make school possible for a "weird" kid and take it away from their own kids, for some reason they always say no. These people do not understand disability (especially Autism). They are not trained educators and yet they get to close the gate to education for disabled kids.

It was decided that Noah should learn to be at school without a TA. He had a lot of melt downs (endangering himself and other students). His mother would have to come and pick him up from school many times a week. For this reason, his mother could not work - we never knew when the school would call and require us to remove Noah from school.

The school started suspending Noah from school when he had meltdowns. This included times when they would do things like take him to assembly (which we had explicitly warned them against because of the noise/social overload issue). The Board of Trustees declared that he would be treated like any other child and so would be suspended when he couldn't cope and effectively would be subject to a three-strikes regime where after several suspensions he would be excluded altogether.

Noah's meltdowns got worse. He hit TAs on a few occasions. We went through several TAs which meant people continually needing to learn how Noah worked - a process which took a lot of time and made things stressful for Noah. A new TA was hired knowing that Noah was prone to meltdowns and hitting. Sure enough, Noah had a melt down and hit the TA whereupon she "quit" which resulted in Noah being stood down. They said that Noah could not come back to school without a TA despite the fact that the TA who "quit" was still working at the school.

Noah's Ministry worker insisted that they hire a new TA but

* The names of people in these stories have been changed for anonymity. IHC has also decided to remove specific school names.

they took months to even advertise the roll and it became apparent that no-one would be hired until the school year was nearly finished. We pulled Sam out of the school and in consultation with the Ministry of Education, started working on getting him transitioned into intermediate school asap.

Intermediate School - we had a TA to help Noah in class. We had regular IEP meetings with the school. The principle came to IEPs and was very interested in working creatively to solve problems.

We had a problem initially with the TA they hired. He was completely unsuitable - he communicated aggressively with Noah (and his mum) and never followed through with things that were agreed to in IEPs. There were other issues - he decided that Noah's diagnosis was wrong, for example. That was fun.

We were told that the TA appointment was an employment issue for the school and we had no say in the matter. Fortunately the school managed eventually to move that TA aside and put in place an experienced TA who was wonderful and things went much much better from there on in.

Noah did really well. He went from having meltdowns all the time and continually having to be removed from school to maybe having one short day a week and a melt down became a very rare event indeed. The things that contributed to this:

- A single TA who was skilled and who wasn't changed all the time (consistency for Noah)
- A single room to work out with a lovely teacher who was patient with Noah and didn't get upset at him (consistency again)
- A time out area that was just used to help Noah, not punish him
- A fantastic team of people at DNI, at the Ministry of Education and their psychologists who all worked together sharing ideas and with a genuine will to achieve a common goal.
- A class of high achievers who were fine with being told to be quiet from time to time and who grew to know Noah and appreciate his need for calm.
- A school principal who was empathetic and was involved

DNI used Noah's specialist teaching funding for a specialist teacher rather than just absorbing it as his primary school had done.

DNI used Noah's 18 hours TA time from the Ministry to actually provide 18 hours of TA time. This still limited the time Noah could be at school but it was nevertheless an improvement.

There were still some small issues when teachers had to change or Noah misread a social interaction between boys being boisterous, but for the most part DNI was excellent and remains Noah's most positive experience with mainstream schooling.

High school is where everything really fell apart for Noah.

We should have taken a hint when they said that disabled kids couldn't attend their open day.

The high school's plan with Noah was to put him in their 'T-Class'. This is where they put all the disabled kids. They don't learn the NCEA curriculum or do what they need to get through high school and get to University. They basically just keep the kids busy - some basic learning coupled with collecting pine cones and doing work experience in menial jobs - sorting rubbish at Salvation Army, emptying seedling containers at a local nursery. The kind of thing that will prepare kids to be a low-achieving member of society. We

(and Noah's representatives from DNI) said that this was not acceptable for Noah on account of him being academically capable, and insisted that he was mainstreamed.

We had IEPs with the high school but none of the senior management team ever attended. We agreed to start with a couple of classes and then build up over time. Noah struggled to attend classes which were very noisy. When he lost control and shouted at classmates about being quiet, the teacher shouted at him. When we asked whether the classes could accommodate him by trying to be a little quieter, we were told that the classes were "no noisier than usual".

The high school provided a TA. However, the 18 hours that Noah was funded for by the ministry was reduced because the high school wanted to pay the TA more than the Ministry funded. Additionally, they took holiday pay out of that. Their policy was not to top up TA time, so the Ministry "contribution" became the only fund for TAs and the amount of time it covered was considerably less than the "18 hrs" that the ministry intended. The high school made it clear that Noah was not allowed at school without a TA. On top of that, due to timetabling issues, Noah could only attend two topics. In the rest of the time, they would go collect pine cones or ride a bike or fill in time doing non-academic tasks with the rest of the T-Class. His mother would often be rung up at any point to come and pick him up because there was nothing for him to do at school.

Months went by, the Ministry of Education asked for Noah's classes to be expanded. Nothing happened. The next IEP, the same question was asked and we were told that they'd looked at the schedule and nothing fitted in. They didn't seem to think that they needed to actually tell anyone about it. We asked what the plan was to expand Noah's classes so he learned enough to get through the curriculum and were told that there was no plan. When pressed, they said that Noah could keep working at the high school at the current rate until he was 21, if need be.

We were disgusted. I could tell that the Ministry of Education people were disgusted. The Ministry came back with the suggestion of Noah doing Te Kura (correspondence school) in class hours with his teacher aide. The school said that they would look at the suggestion. What transpired is that they would not fund more than a single topic and the TA would not help because he "was not paid to teach" (despite being a trained teacher).

It dawned on us that the high school had no intention in educating Noah and were just doing the bare minimum they thought they could get away with. We informed the Ministry that we were going to remove Noah from the high school and we wanted to enroll him in Te Kura full time. We learned at that time that the high school had been stonewalling the Ministry the whole time - when we would email people discussing a meltdown Noah had had or the the fact that Noah was barely managing to get through any class time at all, the school would be telling the Ministry that everything was fine and rejecting every offer of help or suggestion for improvement.

Noah now does Te Kura - correspondence school - at home. He has a Teacher Aide for 10 hours who mainly helps with Math and Social Studies. His mother helps with English and Digital Technology. On Fridays he goes to a local school for some social interaction.

Noah is doing brilliantly. Despite having missed years of schooling through the mainstream system he is working ahead of most others in the system. His teachers report that his work is excellent and of a very high standard. Noah is very

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happy. His stress levels are down, his confidence is up. The future looks bright and we're wishing we pulled him out of the mainstream system earlier.

It means that his mother still cannot get a job - but with how unreliable the schools were, that was never an option previously. This is really tough on a personal level - She used to work and having to survive on one wage is difficult on top of an already demanding situation. But we have to get Noah educated if he is to make the most of the promise that he has.

Emma*

Emma was born with a cleft palate, Pierre Robin Sequence and hypotonia. In the beginning, she had trouble feeding and breathing and spent the first month of her life in neonates. Emma came home with a nasal gastric feeding tube which she had for the first six months of her life. Emma was diagnosed with a rare chromosome disorder 4q 34.1-35.2 deletion by a clinical geneticist who stated in her letter that she would need ongoing support throughout her childhood and schooling. All her milestones were delayed but did eventually take her first unassisted steps at around 23 months old. Her speech took a bit longer to develop and she was talking a lot better by the time she was 4-4.5 years old, but still quite hard to understand at times and was quiet at preschool and when she started at school.

Emma was not toileting independently when she started school and still having accidents. The early intervention team had decided when she was still at preschool that she did not require any help so when she started school she had no help. Her teacher had to deal with her accidents and had to fight to get the RTLB involved to help with her learning.

Emma has been at school for three years now and over that time has received ICS funding of 1 hour per day on and off to help with her learning. She is 8 and still at a new entrant level.

I had an educational psychologist assess her late last year and she scored very low for both cognitive and educational assessments. Her scores put her in the mild intellectual disability range and finds learning very difficult. It is so frustrating to have to battle the MOE for TA time.

With help and encouragement she could progress educationally but because her disabilities are invisible and she is not causing major disruptions in class she is not deemed to be bad enough to receive help. I really am at a loss to understand how a child with a diagnosed chromosome disorder (from birth) is not able to access the help and assistance she deserves in our education system, it is also frustrating for the school and they continue to go into battle for Emma.

I would love to see a more inclusive education system that is fair and equitable for all learners meaning those who find learning difficult should receive the extra help and attention that they deserve.

Phillip*

We have a son, 10 years old, with epilepsy and general delay and a partial speech impediment.

After applying for almost 4 years MOE granted ORS funding.

The school has been nice to us. But as there is no legal requirement for Special Needs teacher aides to have formal studies, a certificate or degree, the school hired any person just with good will or disciplinary attitude to look after our children. One year, the school hired the wife of the School Care Taker. As the woman didn't have the education needed

she got sick and resigned six months later.

My question for MOE, Why our children can't have access to a professional teacher aide? Does MOE know that with a good intervention, the progress of a human being with disabilities can improve? Around a special needs boy or girl, there are "normal students" that are learning how the authorities are being so unfair, they are learning that there are children better than others and they don't deserve an education.

I have the hope that one day somebody with power, brain, and good heart read my words.

Pablo*

We are a NZ family who relocated to NZ 15 months ago. My son is 14 years old with an intellectual disability. We just secured ORS funding last December after firstly being told by his school that he would not qualify so there was no need to apply. I watched my happy boy, who had been fully integrated into the education system in the States and had led a full life with sport, friends and a social life, arrive in NZ, be bullied, become isolated, lose hard won skills and morph into an anxious, ill boy who loathed his life and refused to attend school. Despite the school having good intentions, he was unsupported and vulnerable. Before arriving in NZ my child's life looked just like his siblings. Full and happy with achievements.

We applied for ORS, which was a terrible experience. I was forced to see ONLY my child's deficiencies and shortcomings. My attitude towards him was changed.

We were initially denied funding despite Pablo squarely fitting the criteria. One reason they gave me was that "you had to know that your child would not exceed level 1 of the curriculum by the time they left high school". Well he was certainly on track for that without any support! What a dreadful system that uses that as a criteria to deny funding.

We worked so hard in his early years to achieve the highest level of functioning for Pablo and we were losing skills every day spent in NZ.

We asked for a review and were awarded ORS funding but sadly this has proved to be a blessing and a curse. Without funding, Pablo was to be placed in the learning support classroom at his new high school (rising year 9). I was happy with that set up but after year 10 he would return to the mainstream with no support. Pablo is socially very engaged. He loves people and was super excited for a new start at a real high school. My RTLB and I were shocked to find that after funding was granted Pablo was forced into the special needs unit at the high school and was no longer able to be a part of the learning support class. The special needs unit is a return to the 1980s. Firstly it is set in the middle of the high school with huge signage saying "special needs unit". The children occasionally head to a tech class with the typicals but in reality this often doesn't happen. The 16 children aged 14-21 sit in that unit for most of the day (including most lunch times) and require an ORS funded aide if they are to head outside the unit. Most classroom teachers leave the unit aide and the ORS student to their own devices. The child is not included in the classroom, it is more like the teacher is doing the unit a favour by allowing them into their classroom. As long as there are no behavioural issues they are tolerated. This is a stark contrast to the learning support children who have high school funded aides. The teacher is responsible for achieving a level of competency in learning support children and has a working relationship with the high school funded aides. Our children are merely regarded as being babysat with no expectation

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from the teacher to the ORS child. The two differently funded aides are part of the problem. My child's strength is his auditory comprehension. He is unable to partake in tech/cooking wood work class because of his poor motor control. Tech classes are the only classes he is allowed to do. I am beginning my battle now to get him into a science or history class - as he has had success before with these subjects. I have had no luck - and it will be my first battle of many. The system at this school does not resemble any form of integration.

I have tried to get Pablo included in sport - PE is not an option with the mainstream. Others unit kids have failed at that so it is assumed so will Pablo. I have been told by parents that if even if Pablo was to get a trial, he will be set up to fail. The unit takes the kids to RDA, swimming and taekwondo - as a unit. This is not exercise. I have had no luck talking to the basketball coach to get Pablo included in practices. He is well capable of dribbling and shooting hoops. He desperately wants to be a part of the school. Instead, he is stuck in the unit and the because the legacy of failed integration in the past, it has branded a failure for all children. I know the system was not designed this way and that we have policy on our side - but the reality is very different and the fight is already exhausting.

Our high school is so proud that they provide/"give" a building to these kids right in the center of their grounds. But that is where the relationship stops. Because of ORS, our only option is the unit. Why can't my child do science and be involved on some level with sport? He needs to interact with typicals because that's where he will be when he ages out.

Pablo was on a waiting list since birth for a NZ integrated school. When we moved, the school refused to see him after they read his reports. Pablo has no behavioural issues and bring joy to so many people of all ages. He contributes to verbal discussions in class and often makes valid points. He has a memory like an elephant. He has a lot to offer. The unit love him because he is so socially engaged. They tell me he has changed the atmosphere in there for the better.

Becky*

My daughter got diagnosed 2 years ago. The teacher aide was at primary school 20 minutes a day - she got taken out of her room to play educational games on a computer. Now at intermediate the teachers just have to make it work for her as having ADHD and being dyslexic still don't tick the boxes for needing a teacher aide or getting any funding. Education is a real struggle for her.

Henry*

I have a high functioning autistic son. His experience of school was nothing short of a nightmare and total disaster.

He was not ORS fundable yet still needed one-on-one support in the classroom and in the playground. At primary school, I could never understand how a child could slip through a crack until I saw totally blank books come home. There was a huge crack he fell through.

At intermediate, he only had funding to attend school three days a week for a few hours. He tried three different high schools. Epic fails. He spent a term at one school because the head of the Ministry of Education in Canterbury didn't know where to put him. He did have success at two more schools as it was one on one. But he basically spent his high school years at home. When old enough he went to the Adult Literary Center at one of the high schools. When he joined mainstream school as an adult he was told there was no support.

He has been a victim of merciless bullying by his peers and teachers alike. Even beaten with a 4x2 by six students, and the principal's response was he would get worse on the rugby field.

High functioning autistic students are often not given the support that is needed. The diagnosis rate for autism is now around 1 in 60. There is a desperate need for a lot more education for teachers and students. And a room set aside that has low stimuli where they can work and or de-stress and feel safe.

My son had no business being in a mainstream school without the right support and education for those around him. A child who is severely disabled is more easily identified and support put in place. For a high functioning autistic child the need for support is just as high but not identified. They are dealing with just as much sensory challenges as a severely autistic child. And because they are high functioning they are also desperately trying to cope with the social issues of trying to fit in and get an education. Just look how many commit suicide. My son was almost one of them.

Fiona*

I am the parent of an autistic 6 year old girl. I definitely had the experience of being made to feel unwelcome when I contacted a couple of primary schools about enrolling (one private school). I ended up going with the school we were in the zone for because they were forced to take us on, fully prepared to homeschool if it feel apart. The school subsidised our private aba therapist to come for a week and a half in order to transition my daughter into school. I was very lucky the school agreed to let our therapist in and also that the therapist was happy to do this.

During the course of the first term our second ors application was accepted. The school had been providing an aid out of their budget. My daughter is currently doing half days, she couldn't cope with any longer right now. Of course, the MOE is pushing for longer days...which would be detrimental to her right now. I have been one of the lucky parents I think. I am highly interested in education and homeschool my daughter during the weekend and holidays so she can feel success at school when her aid does more academic tasks with her. The school and I very much work as a team and definitely manage to make the system work...so far. I am always prepared for my daughters anxiety or sensory issues to take over at any point and have to homeschool but so far the half days are working well. I believe our children with special needs need flexible education to work at their level (with goals to achieve) and a 'school day' suitable to what the child can handle (without being pushed to full days by the MOE - this is NOT supportive).

There is no way my daughter would be able to attend school without an aid, although she is quite verbal she is quite disruptive to a class and a teacher would have no hope of dealing with her and the other children. It is only because of the school funding an aid and then our ors application being accepted that she is able to attend school. She is capable of learning and has no disability in this area, only delay.

I put the good things that have happened to us in the education system down to God (some would say luck) and my advocating and speaking out for what needed to happen in order for my daughter to achieve a successful start to school. The school have been amazing, again we are blessed to have happened to end up living in the zone for this school. I have heard on the Autism Nz facebook group I am part of so many parents having to homeschool. There is not enough support for these children, in utopia there would be a behavioural

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therapist at every school and an aid for every child with special needs (if needed). I will also point out that perhaps the current system isn't broken but that it needs full funding (which will never happen). Even with a new system in place, if it can't be funded then it will also fail.

As a last note: I have been a full time stay at home mum/ carer to my daughter for 5.5 years before we started school. I have been employed by the school my daughter goes to as a teachers aid in another area of the school to my daughter. This is the first time I have been back in the 'normal' world and out of our bubble of autism since she was born. It has been so good for my mental health and well being to be back in the work force. I hope our schooling situation will continue on the upward slope for both our sakes!

Fraser* Family

My Husband and I have 4 biological children , the youngest of which is 21 all of whom are doing well. For approximately 12 years we fostered over 75 children. As a result we have permanently placed 6 children that we fostered from birth. All of these children suffer from varying effects of foetal alcohol and drug abuse. Two of them are on the Autism spectrum, three have ADHD, one has emotional de-regularity , and all display varying degrees of FASD.

We are Appalled at the incredible lack of support and resources available from all government departments but more particularly from the educational system. These children are consistently forced to try and fit into an educational curriculum that simply does not cater for there needs. Because our children don't look disabled they are regularly labelled unruly and disruptive and we as parents often feel as if our parenting skills or lack there of are being questioned. Ours home is a very caring , nurturing , Christian based environment and we endeavour to source and implement any and all opportunities available to help them but the resources are simply not available.

Julia*

Our gorgeous 12 year old daughter has mild cognitive disability, brain injury and global delay.

She has never had a planned support programme in education. She has had TA support now and again very irregular and totally dependent on what the school can scrap together. She started year 7 and new school with none. She is set endless goals she has to achieve all lovely aspirations but no support to follow these up. She has had some good teachers doing their best but mostly under resourced pr do not have understanding on teaching SEND children.

She has been excluded from activities based due to not having the resources. She has felt confused and alone in our school system and now fears school.

Teachers are frustrated by the lack of support they get and the expectations on them

I get it. ! Imagine the frustration and pain for parents placing their loved children in a education system broken and in crisis but talking inclusion

We do not need changes we need a complete re think.

Alex*

I am a mother to a high functioning autistic 12 year old boy. This year has been absolute hell due to him having no support and no communication that his teacher aide from last year

had left. Since school started back my son has become violent manic and suicidal. I have had to take about 3 weeks in total off work so far this term due to having to pick him because he has hit himself out of frustration or other children. He has never done this before and is fine when he's at home. I have been begging the school for more support but as most teachers do not have any training my concerns and advice offers to help in class have been brushed off. Thus has serverly affected my mental health and I am struggling to keep it together. Everyday I do my best to set him up to have a good day and hopefully no phone calls. I can't function at work and may have to give up my job which is not good when I'm a single parent and have another child to think of. Serial times my son has suffered severe heat stroke due to not being told to take his jersey off and not eating or drinking because he is stressed. The school have applied for ORS funding so hopefully he gets some because we simply cannot continue living like this.

Tom*

Kid is no longer at mainstream school. Severe (treated) ADHD, lvl 1 ASD, and profoundly gifted. School said he was "an average student who needs to try harder".

Kid became suicidal, not learning anything, and shamed for not completing work well below his appropriate level.

We are now paying for MindPlus and two days a week at an expensive private school, despite doing literally everything we could to work with the school.

We believe in public education. We were desperate to work within the system, and hate that we have been forced out.

A child who is suicidal and withdrawn at nine isn't normal. This is not ok.

My child is only ok because we have the financial resources to be able to survive on one income, have a parent around for the kid, and pay private fees. I dread the thought of where we would be if we didn't have these choices open to us.

Charlotte*

Our daughter has ASD and chromosomal deletion of unknown significance. She is five years of age and started school in term four last year.

She attended Te Pa at OUCA in Dunedin, a small bilingual education centre. This is where she learnt gross motor skills. Like how to walk, at 2 years and 2 weeks of age. How to eat and drink from a cup, how to wipe her table clean and put away her dishes. She also developed a passion for music, water play and Te Reo. CCS provided support immediately that was such a great resource.

We then relocated to Porirua and support changed to MOE. It took a very long time and a letter to the Minister of Education and the Prime Minister to finally get support in Day Care.

The journey to Primary School was an emotional roller coaster. All the Occupational therapy, Physiotherapy, Speech therapy and paediatric assessments, behavioural assessments and psychological assessments, swim groups, walking groups, play groups, music groups, in home support and coaching from IHC and other groups all lead to Primary school.

Our house is a secure fortress with funded security locks on doors, windows, securely fenced and gated as our girl is a runner now. Houdini clips did not work in car seats and doors and windows are locked while we are driving in case she opens the door mid journey or throws all her toys or herself out the window.

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At home we have pictorial calendars and task sheets, food groups, activities and everyday we negotiate with a silent child and pray she eats breakfast. Worried about a food jag kicking in and wondering if her food will ever be more colourful than beige.

Sleep is 50/50. She can cope after a two hour nap, bright and ready to start her day. I wander around with sleepy eyes, set on auto pilot, fetching milk, num nums, water, the Puppy (soft toy, could be one out of one hundred), the Chicken, the Kea, Scooby, night lamp, carry her upstairs, then downstairs, I fall back to sleep, she wiggles her way to a door and unlocks it so she can escape to see Mister Moon, or bounce on the trampoline. I stumble after her and I sing twinkle, twinkle little star underneath the midnight sky.

Then it's morning. She eats breakfast, she brushes her teeth, we dress her and Daddy distracts her while I brush her hair. She can be a screaming, hitting little mess of a child or a calm, sweet little angel. We read her story book and complete her journal. She plays with her BB-8 droid and kisses him goodbye. She says goodbye to the dog, the cat, the fish and Snails. Then at 08:30 AM sharp, she's off to school. We bribe her into the car and she can now climb in unassisted, very exciting. She says, Bye. Then they are gone.

The introduction to school meeting was attended by two Day Care teachers, our Occupational Therapist, a Speech Therapist, a MOE lady, the Principal and Deputy Principal. We sat in tiny children's chairs and the dialogue began about my little Baby starting school. Buzz words like included, supported, caring, funding, ORS swirled around amongst these highly educated people who were discussing our future. The emotional impact was too great for me and I could not contain the tears. To have all these people caring for my girl was a relief. As a Mother to a disabled child, a different child, a special child, my fears were of her being excluded and bullied, running away and getting hurt and lost. Not being able to communicate or express her concerns. That has never happened.

We have had to fight for funding, fight for support, our school has to fundraise to pay for full time support for our daughter because she is allocated ten hours. She is still toilet training and has a tendency to run away. The ten hours is not enough. The school needs a fence. On one side there is a train track next to a main road, then there is scrub and properties, then there is the road and the beach. She needs support to stay at school. We purchased an expensive GPS so we could track her in case she ran away from school. She smashed it on day one. She needs support.

My husband has back pain from lifting her in and out of the car. He now sees a physiotherapist. I get massaged once every three weeks to relieve the aches from carrying her everywhere. We need support.

Education should not be a battle. Parents should not have to fight or just accept mediocre support or responses. Writing to the PM should not be what it takes to get support for your child. Our school cares. Our teachers care. Our Principal cares. Our girl can now stand in front of a group and introduce herself in Maori. She has great support. The kids and parents at school know her by name and people care for her. They are support.

We parents to children with disabilities are exhausted. We are an elite tactical group who learn how to react to squeals and grunts, hands over ears and screaming. Being hit, bitten, scratched and yelled at, eye contact and non verbal cues. We are exhausted. We apologise when crowds stare, we excuse ourselves to change our big kids nappies with discretion, we

don't attend parties because our kids do not get invited, we never make a promise we cannot keep. Our cup is overflowing with love for our Taonga, but we are exhausted.

Please don't make us fight for our children to have the future that they deserve. Please do not make us accept being a minority. Please let our kids be educated the way they need to be with the best resources and support. Please listen to us because we are exhausted.

They are children who should make it through University, into the workforce, travel the world, get married and have a family. Treasure our Taonga. Give them equal opportunities. Let them receive adequate education and give their teachers the right tools and wrap around support to have a positive impact on the entire classroom. Support their Principals and fellow pupils.

They Are Us. They Are Ours.

Teacher Aides need to be paid fairly. They need to be recognised for their great work, patience, tolerance, perseverance and the support they give to the classroom.

They have no set curriculum, they work with what works with the child. They are Speech Therapists, Occupational Therapists, Teachers, Social Workers, they are firm but fair, they are full of energy yet patient. Are they paid the same as these other professionals? Are they invested in as much as these other professionals?

When our daughter sees her Teacher Aide, the whole world disappears and she is happy. When we collect her from school, she is calm and happy seated by her support person.

The reassurance I have knowing that someone is next to her or helping her to achieve, is priceless.

Our School organises Music lessons, Swimming lessons, toy boxes, bubbles, mini trampolines anything to support our child.

Please support our schools with adequate funding. They should not have to compromise quality and safety, they should be enabled to operate like any other business.

The education that is offered throughout these years will develop our children's future and I want my child to become all she can and I refuse to accept anything less than excellent.

Schools should be fundraising for new equipment and trips to the Museum not to be able to pay for Student Support.

Respect, Integrity and Purpose should be equal for all people, especially our vulnerable.

Please, I urge you to hear and listen to our children who have no voice. Please see us families who walk this lonely road. Please have empathy and care.

This story is a snapshot of our current everyday life. We have come to terms with the fact our child may never leave home, she may never have a family of her own, she may need my help to toilet for the rest of my life and one day I will die looking into her eyes and my biggest fear will be that she is alone and no one will care like I do.

You can care now. can give her the tools to enable her to leave home, start a family, toilet by herself and to comfort me when I am dying by looking into my eyes and telling me that she will be ok.

Will you help her be OK?

Patrick*

I have a son who is ASD. He has been severely bullied for his lack of understanding social situations. When someone laughs

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he thinks they are laughing with him. He schooling is so far behind that they gave up on him. He is not severe enough to qualify for any funding.

He has now developed anxiety about school, we tried to change him but nobody would take him with his Autism and ADHD, not unless he had ORS funding or only went part time.

As a result the only choice left to me was to put him back in the school where he was being beaten up, or home school him. All of this being my responsibility even though it's the law to provide education and safety for students. I'm tired, I'm sad, I'll now never own my own home and we will be a single income family for many years. I would love for my son to be given a place where he can learn and have what he needs to look after not only his education but his well being.

Mason*

My story or my son's is not the best. But not the worst. He has not been stood down, he is a "managed" child. With no support.

Since his first school in year 1, he has had teachers tell me he is hard work (needs extra attention) rtlb people tell me " even if he was diagnosed with Autism, he would not get funding/ support where I was not even saying anything about money, just understanding. I have been told his being bullied and abused is at every school and normal! And that if he did do x y z he would not be targeted. By his first principal. After a year and a half of horror and my now then 6 year olds spark gone. I removed him. I then had moe tell me I had to take him back. The school that was open zone did not want him. Ten weeks. He was allowed in, but only cos the moe told them they had no legal rights to stop me. That principal also told me that in the 5min she had met him she did not think he was this and that an he'd get no funding. Apparently her being a teacher over rides the medical professionals diagnosis all because she did a few courses on it.

Before he was allowed at that school, I tried to get him into another. Via an exception, nope. I tried enrolling my broken boy, ridden with anxiety with the kura, moe says NO!

Once he got into that school the teacher comments about how full on he is and he needs alot of attention/help. Yes no one applies still.

We moved house the day after year 2, so he started his current school at the beginning of year 3. They also said no to holding him back because he was too tall an be bullied. Well he is still bullied because the kids know he is different and they very slyly tell him and exclude him.

They however got the rtlb, and an OT report. this stated he needs help, he needs quiet ... He needs one on one etc etc he also needs an iPad as his fine an gross motor skills are not great. Well all year three all this awesome stuff was happening, the rtlb says yes yes he is eliga and. Then at the end of the year. It's a no. Bullshit excuses and he is still struggling. Not only with social, emotional, no support, no funding, his physical stuff too, nothing. Absolutely nothing.

My son hates school. And that should not be. He skipped to school the first 6 months. Then it all changed. No support ... Work got harder. He is struggling. He needs support. He needs to be taught the way he learns not the way things are being taught. He needs understanding of who he is not " your year 4 now, you can do better then that!" He can't, he tries, 110% ... And still falling short in the educational system. Why? Because he does not have melt downs, because he has a thing for rules and will follow them ... Because he has learnt that teachers don't listen to him, that bullies get away with it and the work is

too hard so why bother. He now thinks he is not good enough, he is stupid and alsorts because he sees these other kids work. Again, not held back to be given a chance to succeed an catch up maybe. To make friends? Nope. I had an 8 year old girl chat with me last week. Telling me " just because he is different, does not give the kids and teachers the right to treat him badly" she follows on to say " you know they bully him and are not nice to him aye? Just because he does things differently "

This coming from an 8 year old is eye opening. Please let it be yours! My son is 8.5 years old. He is a good kid and will succeed given the right supports. If he is not, then you may end up with another child on the wrong path or School drop out. Help me help my son be the best version of himself that he can be. NOW! He has already missed out on the last 8.5 years of help an early intervention, because he is not deemed bad enough! Shouldn't we be helping these kids in this grey area ... Who aren't bad enough to fall closer to the average or exceed expectations because they were taught in a way they got it! And thrived!

Grace*

My daughter is autistic diagnosed at 7. She has been to 7 schools in this time is now 15 years old. In this time the 2 mainstream schools she attended she was bullied and her special needs insufficiently supported. I was told by one Principal that my daughter was manipulative! This is a child who has an intellectual disability is autistic and has speech and language problems and sensory processing disorder. Her needs have not been met properly until now but it has cost us a lot of grief and stress and her mental health has declined.

She has been rejected by CAMHS 3 times. We were forced to apply for a loca school near us here in Nelson which is residential.

It has broken my heart having her away from us as a family, but the last setting she was in was not handling her properly (special ed dept.!!) she was running away, melting down in setting becoming explosive, nail biting skin picking and although numerous suggestions by us as parents weren't always followed or adaptations made, we were forced to withdraw her last November. She was being dealt with punitively and inappropriately and therefore failing to engage because her needs weren't being met properly. She then became oppositional. When I basically had her at home with me until February when she started her new placement. I am exhausted and now have adrenal fatigue and don't sleep at night due to stress of her not being looked after properly. Can I just say that the MOE also rejected our 1 st application for Salisbury Girls as there was insufficient data, even though everyone in our community felt she would be the perfect fit. We had to fight again for an appeal, how stressful. This provision is exceptional and extraordinary. I want to know why the MOE can't offer it up as a day provision to take some of the weight of children struggling in other settings as they are restorative based in their practice and very child centred. It would be an economically positive decision to do this to help support other local kids as the Special Ed Dept is heaving with 43 disabled kids in there with a variety of disabilities so overwhelming for many of these individuals.

Lucas*

I have a 5 year old with moderate ASD and GDD as well as hyper mobility which affects fine and gross motor skills.

He started school with no support from the Ministry because

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he is too high functioning. He has language delays and didn't speak until he was nearly three but because he now has some language he doesn't qualify for funding. He's expected to go to school and self-manage even though he has the mental age of a 3 year old.

On week two of school he snuck out of singing syndicate because the noise was too much for him. No one noticed he was gone and when I went to pick him up he was in the sand pit and not with the class. Its terrifying that without a teacher aid he could abscond and walk himself home. We are now having issues with him becoming over stimulated or excited and hitting or kicking other children.

His teacher is amazing but has little to no resources to support him. I've had to start picking him up early because of the lack of support which means that I can't go to work. This situation is financially stressful for our family. My husband works 6 days a week when he can so we can pay for everything we need including the extra therapies for my son.

We have finally managed to get 1.5 hours of teacher aid support on an interim basis split between our son and another ASD child. This isn't good enough as there are several other kids in the class with special needs and behavioural problems. An elderly woman from our community volunteers almost full time in the class at the moment. The ministry fails to look at classes as a whole. It's totally unacceptable that his teacher is meant to teach that class with 1.5 hour of teacher aid support and accomplish anything with all the high needs going on in the classroom.

This problem could literally be fixed by money. If our schools were properly funded my child could be at school full time and be supported with improving his social skills. We work so hard with him at home but it feels like such a wasted effort when we send him to school and no resources are put in place to support consistent strategies. Lack of resourcing also means he can't take breaks when he needs them because there is no one to watch him outside the classroom. would do so much better if he was given time to run outside when he needed it but with our current support levels this can't happen.

Alicia*

This is our daughter's second year out of high school. She started school at six, in 2002 and finished at 21, in 2017. She has physical, intellectual and sensory impairments and was ORS funded through school.

We lived in a small community and after our daughter had been at the local primary school for six years, we decided to leave and find a school that was (more) inclusive. Staff at the school didn't listen to us as a family when problems arose or we wanted them to do things differently. They expected our daughter to fit in to what was already happening and the way they did things. When things didn't work for her, they would just carry on as usual or they would exclude her from the activity. They didn't work in partnership with us as a family. They saw and treated us as 'difficult parents'. We tried lots of different things to help the school understand and practice inclusively. A few times we tried to get help and support from the Board of Trustees, but they usually backed the school principal who was unsupportive and antagonistic towards us. This damaged our relationships with some members of our local community. Most Board members didn't understand inclusive education or our daughter's entitlements and rights so there was no leadership for change and improvements. My partner was on the board of the school for 9 years (he was elected 3 years before she began school), but that didn't make

a difference to our daughter's experiences either. The regional manager of the Ministry of Education and our daughter's lead MOE person told us they couldn't intervene because the school was a "self governing body". They indicated that if she had been refused enrolment, they could act, but they could only encourage schools to change practices and remove barriers to participation, not require them to. We received the message from teachers, the principal, MOE and other families that we should be grateful that she was at the school and not to rock the boat and were made, to feel that we were unreasonable and demanding.

It is now 11 years since we left that school. The school has a different principal and teachers but I have recently spoken to a parent of a six year old boy with Autism who is blind who moved into the community. The school refused him enrolment and his mother has moved to another community and he has returned to the special school he had been attending. He had months at home without schooling while his mum tried to negotiate his access to the school and they had moved communities to be there. Where was the MOE with their promise of least enforcing the right of disabled students to attend their local school?

You can contact me if you would like and/or need to. nga mihi, you're doing great work :-), Bernadette

Because we lived in a small community, leaving the school meant we had to sell our house and leave the community we had been living in for 20 years. We ended up moving from the south island where we had family and community support to the north island to make our move work financially. We found a school we really liked in the new town. The school was much more diverse and responsive to diversity, but the school employed a teacher's aide who was anxious and who would set and enforce rules more than the school did and the TA worked in ways that isolated our daughter from her peers. We ended up asking the teacher to deploy the teacher aide across other classes and children so that our daughter didn't have her around all of the time.

The discrimination my child experiences directly effects our whole family and has and continues to be tough on my mental health and well-being. A year after she had begun secondary school, I had a nervous breakdown because of the on-going stress over many years, continuing problems at each new school, feelings of disempowerment and frustration and the isolation I experienced after leaving my support network in our old community and trying to establish new relationships and connections for myself, my child and our family.

The secondary school we chose had and continues to have a reputation of being inclusive of students with disabilities, but we experienced a lot of exclusion at the school. Whether she was included or not depended on her teachers. Some subjects and teachers would work hard to teach her and support her participation and learning. Other teachers would leave her education to teacher aides and basically ignore her. These teachers saw her and her education as the responsibility of the school learning support staff, and not themselves as the subject teacher. Twice teachers attempted to refuse to have her in their subject or classes, especially in senior years - we wouldn't take no for an answer, but it back fired because the teachers didn't want her there or know how to teach her, and so she would usually not get much out of that subject anyway.

Many teachers didn't know her sufficiently well and would have very low expectations of what she could achieve. This meant that it wasn't until she was in years 13, 14 & 15 that we managed to convince some teachers that she could achieve NCEA credits. Up until then they had not

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considered or included her in NCEA assessments. It was hard to communicate and keep up with six different teachers who changed every year, especially when most didn't see the benefits of or feel like they needed or had time to communicate regularly. It was generally us who would approach the teachers, not them contacting us. We usually felt like we didn't really know what was happening. The school beyond the learning support staff wasn't easy to approach, especially the teachers who didn't really want to talk with us about our child and how to include and teach her well.

There were also different rules for her access and participation in extra curricula activities such as school trips and camps and musicals. Some examples are, only being allowed to stay on camp one night instead of two because the activities planned for the second half were too physically demanding for her and no 'alternative' or variety of activities was planned, we were often not informed about opportunities such as overseas choir trips, Music camps, music and drama performance opportunities that our daughter could have been part of so she missed out on a lot of things that other students and their families had access to and enjoyed.

After she had left school, we approached the Principal to ask for an exit interview so we could talk about concerns we had about her education with a view to the school learning from our experiences. The principal told us that s/he hoped we would have something positive to say as well. It is just so deflating when you are perceived as negative and complaining when all you are trying to do is share your perspective and support your young person's education. It's like living on a different planet to come up against one barrier after another in a school that has a reputation for being inclusive and responsive to diversity. It makes it hard to keep on advocating and necessary to pick your battles and we really have felt very much alone and isolated as a family in our struggle to secure what our child is meant to receive as of right and for her to be valued and respected.

Matthew*

Our story is we are happy with the way our boy is treated at school, but also know there is more that could be done.

It took 3 goes to get ORS funding, yes 3 attempts. On the 3rd we got very high needs. We were told by some, to wait until he was 6 before he started school. The thing was though, he was bored at preschool, he had his teacher aide, but no one really played with him and the preschool wouldn't let him go on outings. Then he started primary school. I have to say they have been great, they have a specialist reading teacher that he sees for 1/2hr a day, and she has had a huge amount of experience. He is now in year 4, his year 2,3 teacher was amazing with him. I'm undecided about his year 4 teacher. Along the way he has had 2 consistent teacher aides, one for 3 years then the current one now who is also fantastic. Many of the teachers are warm and chat with him, the senco/deputy principal have a lovely relationship, and he gets included in most outings. So positive mostly. But. But he is still not at school full time, he finishes at 1.50pm Monday to Thursday and has Fridays off school. This is how far his ORS funding stretches. I have been told the school has tried to get more funding, but haven't been successful. There are other ORS kids and other kids with disabilities at the school too. This in itself is frustrating. I feel that it is not the schools problem but at the same time it is. The school is supportive and have tried having him with out a teacher aide, it just does not work. So we are left, I can not work a day time job as there are not many 9.30-1.30 jobs out there, instead I am self employed, this too

is extremely stressful and my income is almost non existent. Then of course Friday's. I have been told by the ministry I have to home school him on Friday's..... what a joke, no support from them, the school has given me access codes to his reading eggs program, but no, I will not be doing this. I am not a teacher, let alone knowing anything about teaching. So we do other stuff, like house work and go out and about so he learns other stuff that can not be taught in schools. I still feel insulted that the expectation from the ministry is for me to be teaching him. The other affect this has is he has no actual friends, he desperately wants friends, but he's not at school full time. And although the school has a culture of inclusion, you can't force neurotypical kids to play with the slightly different kids. He's a beautiful smart boy, who I feel the school is supportive, but their hands are tied to a certain point. I keep being told we are lucky to have a good school, but it should not be luck. The amount of time and energy and been 'vocal' to get what my other kids get naturally for my different boy is ridiculous. The system is beyond broken and it does need to be changed so all our children are included and get what they need.

Rosie*

Our daughter was diagnosed with Autism at around 3 years of age and then about a year ago began having seizures of all kinds. Recently she has hugely regressed in her abilities, can no longer walk down steps, feed herself, often falling over, and she has begun having drop seizures which are occurring multiple times per day. She had been attending daycare but Ministry of Education wouldn't budge from 5 hours support per week. Over the past 2 weeks she has had to go to hospital to have her head glued due to gouging it when falling at daycare and then grazed her cheek bone amongst numerous head whacks. She is covered in bruises. I don't want to take her back as she keeps getting hurt. I called the Ministry of Health and Nasc but they say they can't help as Epilepsy is an illness not a disability. We are working with the Paediatrician on getting another diagnosis but it will take some time and we are just expected to wait?

Adam*

NO, we are still not there yet!

It saddens me to learn that 22 years after my son started primary, aged 6 years, there are still restrictions regarding contact times for some children to attend school. He was on restricted hours for attendance and I was also required to attend lunchtimes to monitor my son, every school day, which did not change until the Principal changed. The internal struggle to keep him mainstreamed so that he could learn to interact with his peers, and conversely so they could learn from him, was a constant every day whilst he was at primary. His first birthday party invitation came in Year 7 which was so worth our persistence to mainstream him at that level of schooling.

Zoey*

My daughter is now 28 but was when she was ready to attend a local Girls High school the Principal initially said they were not set up for special learning needs like my daughter has. I just said back to the principal that they needed to get set up because they were the only Girls school in town and that is what I wanted. Anyway my daughter did attend the Girls school for her 5 yrs and she always had full teacher aide help which started off in the classrooms and then changed to

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working mainly in a room by herself which wasn't mainstream education at all. The teacher aide was excellent and always got my daughter involved with out of school activities and trips. I would have liked her to have extra help with speech and all her work came via correspondence which a lot of it was too difficult for her. I also heard that her specialist fund allocation was not being spent on her as it should have been. This was in the years 2003 to 2008 so I do hope that school has improved and welcomed special needs students and used their funds appropriately since. My daughter after high school attended a local poly tech that supposedly had a life skills course for people with a disability. It ended up being for anyone and had able bodied very independent persons attending that stole from other students and intimidated them. The support wasn't there and students were given credits for doing nothing. It was a complete mess and tutors were not good. I pulled my daughter out after 18 months as it was meant to be a 3 year course. My daughter went into a severe depression from the stress of attending there and has taken 4 years for her mental health to come right and she still has not regained her skills or speech she had before attending that polytech which was funded and run by the government. Biggest regret I have is letting her attend that place. Our NZ education system is definitely got its issues and I do hope some of them are getting sorted. I now use IF to get my daughter the support she needs. So far this is working but with her still living at home my next step is to get better support for her to live in a housing situation of her own but with support of our choosing.

Aiden*

My son was diagnosed with autism at age 5. In the beginning I had to be handy as the teacher who didn't have any additional support or teacher aid would at times call me to take him home. I did a lot of parent help so I could support the teacher and was required to go on all school camps and trips. The funding at our school was divided up and mostly paid for reading support. Aiden was not given a teacher aid at all during his time at school. When he had problems (in the playground) a teacher was asked to supervise him. He really needed some social skills training and support. A lunch time group or activities teacher would have been great. The school Chaplain was great for Aiden and together they worked on activities of interest to him. Also when issues occurred Aiden was removed from class to work in the principal's office for a number of days. (He didn't mind this as he was often bullied in class, which caused him to react and get into trouble). Some of his teachers were great but others couldn't be bothered with the extra demands of a child with ASD and didn't know what to do, so would opt for exclusion as the easy option. Perhaps more training for teachers would improve teacher confidence and practice. I don't think information about what worked for Aiden and his assessments were communicated very well between teachers and from year to year.

I believe all teachers should have a teacher aid to work in classrooms and that children's social and emotional competence should be of equal value to academics.

Schools could employ social coaches to work with children at lunch times using games and other activities.

Chloe*

I would love a lot more support for my 10 year old daughter, who is learning at a 5 year old level she works so hard to do what her friends are doing but she knows she's different from her peers she tells me every week she tries so hard, and I know she does. She gets a little support but she needs a lot more, but

because she's not bad enough she gets about an hour a day. She is delayed in all areas so even friendships she finds hard and takes everything to heart. I just want my daughter to have a more support at school she's not going to be a doctor or a lawyer that's OK, I just want her to do her best and that's all I expect of her. It is a struggle for her to be at school she always counts down to the weekend as she finds work so hard at school, but if she had more support she would be a happier kid and she will be able to cope out there in the big wide world when she's older.

Lily*

With a child that has learning disabilities there is a clear need for more teacher aids in class rooms. I moved my daughter to a private school where she could get more one on one time and had her in extra tuition for 6 years to get to the academic level of her age. I was only able to do this due to financial support from others. It's incredibly stressful as a parent not having this support in the education system.

Dylan and Abby*

My grandson has dyslexia, dysgraphia and dyscalculia. This was not discovered until he was 2-3 years into his primary schooling, and my daughter and son-in-law paid to have him diagnosed by a psychologist. They have since spent quite a bit of money on tutoring and finally discovered swimming and surf life saving, both of which sports he has excelled at. He is now a much more confident boy (at age 12) and his learning seems to be slipping into place. He talks about going to University and so obviously no longer considers himself to be "dumb".

His journey from a new entrant at school was not so smooth. From a gloriously happy few years at Kindergarten, he entered school with a teacher who totally misunderstood him. He was found crying on the field during class time by another parent because his teacher had sent him out for being naughty. This boy was struggling to keep up with normal learners and by the end of a 6 hour day was exhausted and would melt down when told off. He was routinely punished and he learned to hate school. His parents were repeatedly told there was no funding for children who "seemed to be coping" - the funding had to go to obviously disabled children.

His second year at primary school was spent with a teacher who "got him". She made herself trustworthy to this little boy and he started to progress. He still had meltdowns, but was not punished.

By the time he had almost finished primary school, and had benefitted from diagnosis and tutoring and a few more good teachers, he landed another teacher who almost undid all that good work. She labelled him "dumb" to his face and he lost heart with school and his own hard fought abilities. This teacher was frankly, too "tired" for her job and should have retired perhaps 5 years previously.

My grandson left primary school for intermediate and has done better mainly because he is more mature. He is being encouraged to play the drums and his out of school water sports are hugely encouraged by our three generation family. He is a popular student and his learning is progressing moderately well.

The First Assistant at his old primary school was a good influence on my grandson. He learned his name along with the other 500 or so kids and always greeted him in the playground. Lately this man has explained to my daughter and son-in-law how they had to ration funding for special needs

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children and was rather apologetic. I think it is important that teacher aides are funded, but it is more important that individual teachers are taught during their training and at professional development, that learning disabilities are to be believed and taken seriously. Teachers cannot however do much if a diagnosis is not made - though some are well aware of a child's handicap because they have made it their business to read up about learning disabilities.

I know that there is an ongoing disconnect within the Ministry of Education that has led to learning disabilities being questioned and not recognised, and certainly not taught in Teacher Training. This is a Ministry problem and is appalling. The children and their families, and the enlightened teachers and administrators, deserve better.

I now have a Downs grand daughter, albeit she lives in England. I am learning so much from her, from her parents and from the society's response to children with visible learning and health disabilities.

I work for a family who have a child born severely disabled and who didn't learn to speak until she was 9. She is now working hard and with great joy with an Occupational Therapy student, and is doing her Duke of Edinburgh Award. This young woman is a truly wonderful result of family input and dedication over many years of hard work and home schooling.

It is dedicated parents, grandparents and teachers who make the difference, and where they do not exist, or can no longer cope, societies such as IHC need to step in. This makes NZ a civilised society.

Turner* Family

I have 2 children with ASD/GDD, diagnosed at around 3 years old. Although I'm very grateful for the diagnosis and support given from the MOE/SE I have struggled through the years with school support and feeling like my children were not understood or accounted for, even though I worked at the school and tried my utmost to make it work. My children received ORRS funding at 12 years old and therefore I was able to have them removed from mainstream and now are doing much better at a special education unit within a mainstream school. As much as I employ and support the idea of mainstream/inclusion of children with special needs I believe the schools need more support and education regarding to the unique requirements of these children as I have truly endured a lot of emotional suffering and isolation through the years.

Laura*

Our daughter, Rose began at a full Primary this year going into yr 7 as her previous primary only went to yr 6.

The school had, although given her file etc and Rose being transitioned for the entire of term 4, not put ANYTHING in place for her. They did not warn anyone etc of a second powhiri within the school, but forced her to go to it.

This, along with some minor incidents during the day resulted in a major meltdown and Rose assaulting several staff, who had not read her safety plan from the previous school (as they hadn't implemented one at the new school). This resulted in Rose, an ORRS funded student, being stood down then asked to return only for part days. At the end of this the school pushed, knowing it would send her into a meltdown, Rose lost it so they called the police on her the illegally suspended her (proven to be an illegal suspension). This was lifted but we were told she was not safe to attend school! In total Rose has

attended 2 full days of school, and 8 half days for the entire of this year!

We are currently negotiating with the MOE about another school for her to attend.

Jack*

I have a 16 year old who is actually still in school. This in itself is a major feat as he was excluded from his first 2 school, the first one for not having enough funding and the school were asking us to pay for a full time teacher aid - and by full time I mean from stepping on to school grounds in the morning to leaving the gate in the afternoon - I don't think anyone except those in special school get that much funding.

The second school he was excluded for hitting a boy who had been taunting him for several years, the school knew this but did nothing to avert it.

He is now in a school that is better, but still has a long way to go even though they have a special needs unit (which we are not allowed to call special needs, we have to call student support even though all the students there have a diagnosis of some kind).

We are working with (and battling with) the school on 2 fronts.

The first one is full year inclusion, as with most special needs children that make it this far he is doing NCEA but we have chosen subjects that are internal assessment only, however we have been told that he needs to go on study leave in Nov with the other NCEA students who are sitting exams. We questioned this heavily last year as a full term without learning for an already slow learner seems like a silly idea. He was finally granted the ability to go to term 4 and cover topics he needed help with throughout the year, so it was used as a catch up session which is what we wanted. He was only granted this after going up 2 tiers in the ministry of education - the school finally gave in. However, the school are now saying this was a one off and we have had to start the process all over again for this year.

The second one is expectation. The school appear to have a policy to get all special needs students out of the door as soon as they are in year 13 (regardless of where they are from a learning perspective). We have had this conversation more than once and have told the school that we expect him to keep learning and age does not equate to stage as he is doing each level across 2 years. It is only this year that they are finally realising we expect him to stay until he reaches his potential which may be until he is 21 as in the guidelines, but they actively transition most students out much earlier than this (as evidenced by many other students who are leaving without anything to go to).

We are also this year just getting some understanding from a few of the teachers that he is not just staying to gain NCEA credits. He is doing health level 1 which he will not pass, but he is learning great amounts about human behaviour, friendships, treating others well etc, and the health teacher is happy for him to progress on to level 2 without credits, just to continue his learning in this area. He is not good unless he has concrete concepts - so he has the ability to gain credits in other classes such as math, science, food tech etc, but he is learning some really good life lessons in health and it would be great to continue this learning regardless of credits.

Colin*

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Hi, I have been fighting the system from day dot. From ECE when I was told they weren't allowed to help me, and beginning primary school when the school cancelled our enrollment with special education because they didn't see anything wrong with our son and thought they knew better - even after getting a professional diagnosis they still refused to accept it and blame us as parents on his downfalls. To now been excluded from all schooling because the previous principal and last principal refuse to accept MOEs help and advice to support our son in school, instead been told to find a 'more appropriate' school. But when asked MOE told he doesn't qualify for special school he isn't that severe. We are now in nothing land as MOE is saying correspondence is only a temporary thing, and trying to force us to a temporary residential school on other side of country but we keep saying other schools won't have us because of these two principals until that changes we won't be accepted - totally gutted and it's having such a sad impact on our son.

Jessica*

With older kids at our local school we were approached about one of my 4 year old twins. They noted she was in a wheel chair and wanted to discuss her needs for school. At the meeting I was told school was not suitable for her as her maximum ORS funding was 17 hours and that wasn't enough. My daughter would be a burden on the school to provide the rest of the hours she would need. This low maximum amount is the key to discrimination. It should be the full school hours of 30 or even 34 to make kids with high needs welcome.

Thomas*

My son was 5 in February 2019 he has Autism spectrum disorder. He is non verbal and is currently on the waiting list to attend a special school, they are bursting at the seams and it is not known when a start date might be. I cannot opt to send him to any other mainstream school simply because I know it would be a strain and a lot of hard work for the school, his teacher and especially for my son. How can we ensure our children have the best start to school life if there is no support in place. I have two older children in mainstream who would love their little brother to attend their school however even in their eyes they cannot see how it could work. I have assured my children that their little brother had to go to special school where he is best supported with teachers that are qualified to care for him with therapists on hand and a wonderful outdoor indoor flow where the teachers and teacher aids allow him to be himself and support him the way he would best learn. However we are on the waiting list we are on one income because I am caring for my son who can't start school yet, we are managing to get by, WE ARE LUCKY! There are some families who would need to use mainstream because it is their only option as they need to work and what would become of their child in a mainstream? Their child will fall through the cracks if there is no support for the school, teacher and for their child. Let's talk about children who have a disability but DO NOT qualify for support in schools, these children are in crisis and so are their families. Parents are being called up to pick up their children from school because the school and teacher simply are not supported to meet the needs of their child. What happens? parents have to quit their jobs to stay at home with their child and if that is not an option their child, the teacher and the school struggle daily. I cannot say this enough it is a CRISIS particularly with children who do not qualify for ORRS funding. I haven't even talked about the emotional distress and strain parents and their children face

from this crisis. I will end if here because unless someone high up cares enough we will continue to be in this crisis!

Frances*

Our 11 yr old daughter has Kabuki Syndrome. She is awesome, but functions like a much younger child. Looking back on the last six years of primary school education we have had a mixture of success and discrimination. Individual teachers celebrated her, others ignored her and others actively excluded her. Despite this weird semi-inclusion she thrives at school. Her attitude to a system that mostly just tolerates her and doesn't prioritise her learning is "I love school". She has skills beyond the average person, her ability to read people and situations is phenomenal. While the class are writing she is observing, and memorising conversations word for word. I see her potential as a gift. It is a pity the education system has such narrow criteria for success, but she is happy.

Just last week at her new school (intermediate) she received the class award for the week "for her attitude to learning, always taking part with a smile on her face and keeping the whole class organised". She is a proud, respected member of her class. We are winning this year!

Kendra*

My daughter has global dyspraxia which most noticeably effects her speech. Despite communication probably being our most essential skill, she would only receive a speech therapist assessment with suggested activities for the teachers to implement. And nothing to help once 8 years. The assessment did not reflect accurately her abilities and issues as observations were over 2 hours with disregard for teachers comments.

Tessa*

My daughter has Autism, ADHD, and Global Developmental Delay, she attends Otumoetai Primary here in Tauranga, and we have had such an amazing relationship with the school, her teachers, Senco and principal. Just last week, both her teachers, RTLB both attended the Framework for Autism New Zealand with me over 2 days, and we got some great strategies to implement at home and school to support my daughter. Last year my daughter attended 4 days from 9 to 2 so that she could have a break as she wasn't coping with the full week, I worked closely with the school to get support for her and her teachers in the classroom, she is now attending 5 days from 9 till 2.30. We have very strong lines of communication open, between all of us, and I feel as a parent it's about working together as a team to ensure the child and teachers are supported, I know I'm one of the lucky ones to get the amount of support for her. We don't quite qualify for ORS funding which would help the school further but they have worked fantastically with what they do have.

Claire*

My daughter was diagnosed with autism aged 4 1/2. We applied for ORS funding 3 months before she started and were declined. Without ORS funding she was accepted for RTLB and high health needs funding, both of which are temporary and can be cut at any time. While the school we chose to start her with was great - it wasn't equipped for high needs and she escaped across a busy road. We were then told that they couldn't keep her safe (after 6 months of telling us they could keep her safe). We decided with the school it wasn't safe

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for her and after reapplying for ORS we switched to a bigger, more experienced school! The month after arriving at Grey Main (new school) we received a letter approving her for ORS! The relief was immediate. The new school environment is inclusive, experienced and empathetic to any needs she and others have. She is integrated into the mainstream classroom with the option of a low sensory room for times when she needs to recharge.

Having been on both sides of the fence funding-wise, I understand how stressful and upsetting it is to only be allocated a certain amount of temporary hours when a lot of these children need fulltime support to reach their full potential. More training for staff and schools is needed to understand and cope with special needs kids and their behaviours. The funding is severely low and ultimately letting these children down, how they can reach their full potential on such limited support hours? It is not realistic. Since receiving ORS funding everyone has seen a massive difference in my child - she is thriving and settling into routines and adapting well. The school are very set up for her needs, have a lot of experience and are supportive, understanding and sensitive to our needs as a family unit. They send their staff on lots of training courses and have a good special needs unit in place. After such a stressful and overwhelming start to her school years, we are now in the right place and couldn't be more content and happy. I see a lot of families who need the support and aren't getting it which is unacceptable. The education act states inclusion and unfortunately this couldn't be further from the truth. Drastic changes to both funding and the criteria to get funding need to be assessed urgently in order for these children to be included and treated fairly.

Ben*

My beautiful son who is 5 and is on his second term of school and still is only getting to attend for 15 hours per week. This is so ironic considering children with ASD and fetal alcohol syndrome need more help and support. We get ORS funding at high needs due to cognitive delays and speech delays and toileting issues. Mitchell was born to an addict birth mother who was trying to kill him in the womb he had IUGR and was born 6 weeks early. We were so fortunate to be able to get guardianship and parenting orders for him. He is thriving in so many ways. We just wish he was given the same opportunities in the education system. Why is it do hard?

Lauren*

My concern is so many children with Disability and Challenges that don't meet the criteria for ORRS Funding because they are high functioning. Get left behind too hard basket. This is not inclusion or supporting the families that are being proactive. There is a huge gap and serious under resourcing. There needs to be a big change. Support and Inclusion needs to be a priority

Williams* Family

I strongly believe that children with disabilities should be in inclusive schooling systems. Considering my brother went through an inclusive education system his whole life he is a lot better for it.

If you separate children with disabilities at a young age then they will feel further apart from society.

EDUCATION PROFESSIONALS

Teacher Aide

I've been working as a TA for the past 5 years in a one on one role with a very high needs Cerebral Palsy girl. We made huge strides in her communication and found that she has a huge cognitive capacity to learn, more so than the specialists had noted in her initial assessments. Working alongside SLTs, physio and OT she has come along leaps and bounds to the point where two years into my work we gained another two very high needs girls in wheelchairs from other schools wanting the same level of care and attention. Thus far we have a team of 4 TAs working with the girls (I work with my initial girl every morning, two afternoons with a 14year old CP girl and 3 afternoons with a 10year old CDKL5 girl). We also after a lot of work finally have an ORS teacher for all 3 girls. We have found that whilst the girls had a very good time integrating into the junior classes, as they have gotten older inclusion has become more and more difficult. We find that we don't have the access to the specialists we feel our students need on a regular basis, instead waiting for months for equipment to be adjusted due to growth or even that jobs have changed and we are left without any help at all. Personal development training courses are very rare and what we do find we have to seek out on our own with no real commitment from the school as training is "expensive" and we are just

"TAs". We as a team feel that better wraparound support or even a resource library where we could source things like tactile objects, communication tools/devices that we could trial before applying for funding rather than buying supplies out of our own pockets to trial on the girls would be beneficial. Our job is already tricky enough with all the care that goes into tube feeding, cleaning, changing, seizure management etc without having to add planning for school trips, safety plans for outings, changing up classroom curriculum to be understood by our students and more. Inclusive education is brilliant when it works, and for the first few years it really was inclusive, however as our students grow and as their need to learn skills that can serve them once they leave school I feel that perhaps special schools in the provinces may be the best way to deliver the care, learning and support that both the student and TA both need. It's not about the money, as we all know TAs work for the love of the job, it's about being able to deliver the best care and education that we can, and I think training, support and education for ourselves would go a long way to helping us provide that.

Former Teacher Aide

I was a teacher aide for a main stream school and my contract was fixed, this was before the new changes in the recent

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budget.

So many kids miss out as they don't meet criteria and aren't getting one on one as a teacher aide does more than meets the eye.

I have a son with special needs and have more experience than someone who is starting from scratch.

It's upsetting that some schools are employing teacher aide staff with poor English amongst other skills.

I feel we haven't been strict enough with aiming to have suitable aides helping our kids.

I'm grateful that through the specialised schools it's on going training at mainstream it's very different and it shouldn't be that different as all kids have the right for support and to learn and so do teacher aides/learning assistants.

I was shocked in mainstream that a teacher aide had no clue how to help a child with learning difficulties.

Former Volunteer

I used to volunteer as parent help at our local primary school. The kids with "behavioural Issues" were often neurodiverse, but there was no funding for help. However, I undertook research and training on Neurodiversity for my own benefit, and offered my help to the school for free, as well as resources from reputable sources like Sue Larkey and Tony Attwood, but the school refused all offers of help. Of course funding is going to make a difference, but there also needs to be an attitude change for a lot of school communities first.

Teacher

I am an additional support teacher for ORS children and they don't get the help and support they need. When I am there for mostly 1 of the week I am there support so the school can utilise the teacher aide hours when I am not. Most of the kids I support are lucky if they get 10 hrs a week. So if the kid in the wheelchair who needs support to go to the toilet needs to go in the afternoon who is there to do that? I find it rough to watch. Equal access to schooling. What about basic needs. It's a joke.

SENCO and Deputy Principal

I am a SENCO and DP with 3 students with Down Syndrome

that attend our school. They are so inadequately funded that our school uses up its entire SEG grant supporting these three students and have no left for our other learning needs students. ORS does not provide enough support for our children. I wrote a letter to Mr Chris Hipkins and was deflected to Tania Martin, her response was offensive. Our school strives to be inclusive and we are but our students are not adequately funded. I would like to share my letter with you and their response.

Teacher

I am a teacher and felt confident that my son would settle well into school with my help. But he was quickly identified as struggling, it was suggested he may be autistic and that we get him assessed. Referral was an arduous and scary experience. When we finally saw the professionals, they had no clear answers for us. By then my son was in trouble daily for his outbursts and meltdowns. He had difficulty with relationships and only one friend. Parents kept their children away from him. Teachers yelled at him and punished him increasingly harshly for not improving his behaviour. It took three years to get an ADHD diagnosis. Although RTLB were involved, the teacher could not or would not implement the accommodations suggested. He kept getting in trouble and believing he was stupid. When he had a full assessment, he was diagnosed with dyspraxia, dysgraphia, dyscalculia, dyslexia, ADHD, SPD. Teachers really struggled with this information because they did not know about these conditions. I felt responsible for educating them, when what I really needed was support and reassurance. The RTLB service funded a teacher aide and the school matched the funding to get him 10 hours per week. This was dropped to nothing when he was 9 because the RTLB judged that his behaviour had improved. The school had to fund the needs of more severe behavioural needs and underfunded ORS students. My son has an understanding teacher, but no assistance of any kind. He doesn't even have assistive technology. I am heartbroken that I am supposed to be happy that he isn't having regular meltdowns. But I know he is intelligent and he has years of falling behind to catch up on. This experience and my professional experience make it clear to me that our education system is woefully under-resourced and broken. Children's rights to an education are not being met!

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- Ainscow, M. (2005). Developing inclusive education systems: What are the levers for change? *Journal of Educational Change*, 6(2), 109–124
- Ainscow, M. (2012). Moving knowledge around: Strategies for fostering equity within educational systems. *Journal of Educational Change*, 13, 289–310.
- Ainscow, M., Dyson, A., Goldrick, S., & West, M. (2012). Making schools effective for all: rethinking the task. *School Leadership & Management: Formerly School Organisation*, 32 (3), 197-213,
- Ainscow, M., & Messiou, K. (2018). Engaging with the views of students to promote inclusion in education. *Journal of Educational Change*, 19, 1–17.
- Armstrong, H., MacArthur, J., & Holley-Boen, W. (2018). Space, voice, audience and influence: Article 12 as a lens to consider mandy's school experience. In J. Berman & J. MacArthur (Eds.), *Student perspectives on school: Informing inclusive practice* (pp. 55-70). Leiden: Brill Sense.
- Berman, J., & MacArthur, J. (2018). *Student perspectives on school: Informing inclusive practice*. Leiden: Brill Sense.
- Bishop, R., Berryman, M., Cavanagh, T., & Teddy, L. (2007). *Te kotahitanga: Phase 3: Whanaungatanga: Establishing a culturally responsive pedagogy of relations in mainstream secondary classrooms*. Wellington: Ministry of Education.
- Booth, T. (2011). Curricula for the common school: what shall we tell our children? *Forum*, 53(1), 31–47.
- Browne, M., & Millar, M., (2016). A rights-based conceptual framework for the social inclusion of children and young persons with an intellectual disability, *Disability and Society*, 31(8), 1064-1080.
- Cole, S., Murphy, H., Frisby, M., Grossi, T., & Bolte, A. (2019). *Longitudinal study to determine the impact of inclusion on student academic outcomes*. Retrieved from <https://www.iidc.indiana.edu/styles/iidc/defiles/CELL/Inclusion-study-handout.pdf>
- Education For All. (2018). *Priorities*. Retrieved from <http://www.dpa.org.nz/education-for-all-documents>
- Education For All, 2019. Us and Them? They are Us , submission to the Review of Tomorrow's schools.
- Elwood, J., & Lundy, L. (2010). Revisioning assessment through a children's rights approach: Implications for policy, process and practice. *Research Papers in Education*, 25(3), 335–353.
- Florian, L., & Black-Hawkins, K. (2011). Exploring inclusive pedagogy. *British Educational Research Journal*, 37(5), 813–828.
- Gibson, J. (2013). Shaun Markham—a reluctant standout. *New Zealand Education Gazette*, 1. Retrieved from <http://www.edgazette.govt.nz/Articles/Article.aspx?ArticleId=8730&Title=ShaunMarkham%E2%80%933areluctantstand-out>.
- Grant, T., & Matthews, D. (2015). New Zealand failing in educating those with disabilities. *The Dominion Post*. Retrieved from <https://www.stuff.co.nz/national/education/71212213/null>
- Hargreaves, A., & Ainscow, M. (2015). The top and bottom of leadership and change. *The Phi Delta Kappan*, 97(3), 42-48.
- Hehir, T., Grindal, T., Freeman, B., Lamoreau, R., Borquaye, Y., & Burke, S. (2016). *A summary of the evidence on inclusive education*. Retrieved from https://www.researchgate.net/publication/312084483_A_Summary_of_the_Research_Evidence_on_Inclusive_Education
- Hickey, H. (2015). Tātou tātou: Engaging with whānau hauā from within a cultural framework. In J. Bevan-Brown, M. Berryman, H. Hickey, S. Macfarlane, K. Smiler, & T. Walker (Eds.), *Working with Māori children with special needs*. He mahi whakahirahira (pp. 70-84). Wellington: NZCER Press.
- IHC New Zealand v Attorney General* (2012) HRRT (Second Amended Statement of Claim, 18 August 2014)
- IHC (2019, February 12) Good Connections for Valued Lives: Ko te herenga-pai ki te wāriu o te ora. IHC: Wellington
- Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities. (2016). *Article 24: The Right to an Inclusive Education E Koekoe Ana te Tūi Implementation Report*. Retrieved from www.ombudsman.parliament.nz/.../imm_interim_implementation_report_word_final
- Kearney, A., & White, C. (2018). An examination of school “stand-down” through the lens of the United Nations Convention on the Rights of the Child. In J. Berman & J. MacArthur (Eds.), *Student perspectives on school: Informing inclusive practice* (pp. 37-54). Leiden: Brill Sense.
- Lundy, L. (2007). ‘Voice’ is not enough.: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child. *British Educational Research Journal*, 33 (6), 927-942.
- MacArthur, J., Berman, J., & Carroll-Lind, J. (2018). Children's rights and inclusive education. In J. Berman & J. MacArthur (Eds.), *Student perspectives on school: Informing inclusive practice* (pp. 1-20). Leiden: Brill Sense.
- MacArthur, J., Dharan V., & Rutherford, G. (2018, September). “I dunno... sometimes I don't like school, it's not my place”: *Enacting secondary students' rights to inform inclusive teaching practice*. Paper presented at the European Conference on Educational Research, Inclusion and Exclusion, Resources for Educational Research? Bolzano, Italy.
- MacArthur, J., McIlroy, A., & Morrison, T. (2018). What made school so good? In J. Berman & J. MacArthur (Eds.), *Student perspectives on school: Informing inclusive practice* (pp. 111-127). Leiden: Brill Sense.
- MacArthur, J., & Rutherford, G. (2016). Success for ALL? Re-envisioning New Zealand schools and classrooms as places where ‘rights’ replace ‘special’. *New Zealand Journal of Educational Studies*, 51(2), 157-174.
- Macfarlane, S. (2015). In pursuit of culturally responsive evidence-based special education pathways for Māori: Whaia ki te ara tika. In J. Bevan-Brown, M. Berryman, H. Hickey, S. Macfarlane, K. Smiler, & T. Walker (Eds.), *Working with Māori children with special needs. He mahi whakahirahira* (pp.30–51). Wellington: NZCER Press.

- Malaquias, C. (2017). *Three myths of "special education" – Thoughts for parents*. Retrieved from <http://www.startingwithjulius.org.au/3-myths-of-special-education-thoughts-for-parents/>
- Mentis, M., Kearney, A., & Bevan-Brown, J. (2012). Interprofessional learning and its contribution to inclusive education. In S. Carrington & J. MacArthur (Eds.), *Teaching in inclusive school communities* (pp. 295–311). Milton, QLD: John Wiley & Sons Inc.
- Ministry of Education. (2014). *Teachers and teachers' aides working together*. Retrieved from <http://teachersandteachersaides.tki.org.nz/>
- Ministry of Education. (2018). *The education and disability legislation guiding our approach to learning support*. Retrieved from <http://education.govt.nz/school/student-support/special-education/education-disability-legislation/>
- Ministry of Education. (2019). *Communities of learning: Kāhui Ako*. Retrieved from <https://www.education.govt.nz/further-education/communities-of-learning-kahui-ako-information-for-postsecondary-education-and-training-providers/>
- Moran, P. (2014). No Learner Left Behind: Is New Zealand meeting its obligations under Article 24 of the United Nations Convention on the Rights of Persons with Disabilities? *Public Interest Law Journal of New Zealand*, 1-42. Retrieved from <http://www.nzlii.org/nz/journals/NZPubIntLawJl/2014/1.pdf>
- OECD. (2017). *Education at a Glance 2017: OECD Indicators*. Paris: OECD Publishing. Retrieved from https://read.oecd-ilibrary.org/education/education-at-a-glance-2017_eag-2017-en#page1
- Office for Disability Issues. (2016). *First New Zealand report on implementing the UN Convention on the Rights of Persons with Disabilities*. Retrieved from <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/un-reviews-of-nzs-implementation-of-the-convention/first-nz-report-on-implementation-march-2011/first-new-zealand-report-on-implementing-the-un-convention-on-the-rights-of-persons-with-disabilities/#twentyfour>
- Office for Disability Issues. (2019). *Key facts about disability in New Zealand*. Retrieved from <https://www.odi.govt.nz/home/about-disability/key-facts-about-disability-in-new-zealand/>
- Runswick-Cole, K., & Hodge, N. (2009). Needs or rights? A challenge to the discourse of special education. *British Journal of Special Education*, 36(4), 198–203.
- Rutherford, G. (2016). Questioning special needs-ism: Supporting student teachers in troubling and transforming understandings of human worth. *Teaching and Teacher Education*, 56, 127-137. doi: 10.1016/j.tate.2016.02.009
- Rutherford, G. & MacArthur, J. (2017). What's wrong with 'special'? Thinking differently in New Zealand teacher education about disabled children and their lives. In K. Runswick-Cole, T. Curran, & K. Liddiard (Eds.), *Handbook of Disabled Children Childhood Studies* (pp. 365 – 388). London: Palgrave.
- Ryan, J. (2006). *Inclusive leadership*. San Francisco: Jossey Bass.
- Selverage, J. (2015). Inclusive education in New Zealand: policies, politics and contradictions. *International Journal of Inclusive Education*, 19(1), 86-101
- Sharma, U., Forlin, C., Sprunt, B., & Merumeru, L. (2016). Identifying disability-inclusive indicators currently employed to monitor and evaluate education in Pacific Island countries. *Cogent Education*, 3(1), 1 - 17.
- Shogren, K., Gross, J., Forber-Pratt, A., Francis, G., Satter, A., Blue-Banning, M., & Hill, C. (2015). The perspectives of students with and without disabilities on inclusive schools. *Research and Practice for Persons with Severe Disabilities*, 40(4), 243–260.
- Slee, R. (2011). *The irregular school: Exclusion, schooling and inclusive education*. London: Routledge.
- Slee, R. (2018). *Defining the scope of inclusive education: Think piece prepared for the 2020 Global Education Monitoring Report*. Paris: UNESCO. Retrieved from <https://unesdoc.unesco.org/ark:/48223/pf0000265773?posInSet=2&queryId=5cbb1fce-23a3-438c-9b47-11f9553aa4fd>
- Smith, A. (2013). *Understanding children and childhood* (5th ed.). Wellington: Bridget Williams Books.
- Thomas, G. (2013). A review of thinking and research about inclusive education policy, with suggestions for a new kind of inclusive thinking. *British Educational Research Journal*, 39(3), 473-490.
- Tomorrow's Schools Independent Taskforce. (2018). *Our schooling futures: Stronger together*. Wellington, NZ: Ministry of Education.
- UNESCO, World Education Forum 2015, Ministry of Education, Republic of Korea (2015a). *Education 2030 Incheon Declaration and Framework for Action: Towards inclusive and equitable quality education and lifelong learning for all*. Incheon: World Education Forum. <https://en.unesco.org/world-education-forum-2015/incheon-declaration>
- UNESCO. (1994). *The Salamanca Statement and Framework for Action on special needs education*. Salamanca, Spain: UNESCO. Retrieved from <https://unesdoc.unesco.org/ark:/48223/pf0000098427>
- UNESCO. (2012). *Addressing exclusion in education: A guide to assessing education systems towards more inclusive and just societies*. Retrieved from <https://unesdoc.unesco.org/ark:/48223/pf0000217073>
- United Nations. (1989). *United Nations Convention on the Rights of the Child*. Retrieved from <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>
- United Nations. (2006). *Convention on the Rights of Persons with Disabilities* (UNCRPD). Retrieved from <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- United Nations. (2007). *Declaration on the Rights of Indigenous Peoples*. Retrieved from http://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf
- Vlachou, A., & Papananou, I. (2015). Disabled students' narratives about their schooling experiences. *Disability & Society*, 30(1), 73-86.
- Wilkins, C. (2015). Education reform in England: Quality and equity in the performative school. *International Journal of Inclusive Education*, 19(11), 1143–1160.
- Wills, R., Morton, M., McLean, M., Stephenson, M., & Slee, R. (Eds.). (2014). *Tales from school: Learning disability and state education after administrative reform*. Netherlands: Sense.



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