

A STATE OF THE SECTOR REPORT 2017

A Youth Perspective on Invisible Disabilities



COVER ART:
Heart on a Star
by
Yaniv Janson



Yaniv's story of 'Heart on a Star'

The centre which is the yellow heart is for love and the red star in the sky is for what they see at night in the sky - when they dream.

The people are shown in different colours to show the richness of feelings in a community. The gold circle shines to give hope.

“ I will not let
what I cannot do
stand in the way
of what I can do! ”

– Jasonspeakz

Acknowledgements

Our thanks go to the individuals and organisations that have contributed to this report, and YES Disability for supporting the collective and ultimately this report.

The collective interviewed many youth and their families. It is their voice informing this report. We thank them for their honesty and their ideas, their wishes and their vision's for a more inclusive, satisfying and rewarding life experience for those who are yet to face the systems that New Zealand currently has in place.

There are others also who have contributed along the way and dropped away for their different reasons. For although we have been instrumental in its construction, we acknowledge openly it's not all about us! For this report, the youth who have allowed us the use of quotes are identified by first name only. This is one way we felt we could respond to the right people and it combines stories and lives in a way (thoroughly researched) that applies pressure to the respective ministries

for positive change and new outcomes to emerge faster and trust that it leads to positive influences on the futures of current school aged youth, as well as the generations of New Zealanders that have yet to follow. The Invisible Disabilities Cube details and the organisations that contribute to this forum can be found at the end of this document.

We would also like to thank the publishers of recently released reports for giving us permission to quote directly from their work to enhance the youth voice and begin an important process to link and enhance New Zealand based research together. Once published, it is our hope that this work will be used as a platform for further investigation from this point forward. The Invisible disability Cube embraces collectivity and collaboration in all areas. Individually we stand alone, collectively we gain the strength of the many to demand change for all youth who live outside the mainstream square.

“ The Traditional medical model of disability tends to create a dichotomy between those that are normally abled and those that are disabled. This is problematic because it conflates the presence of a spectrum of abilities and needs present within all students and risks schools taking a narrow view of identifying which students need support. This is a particular risk if a student does not have an identifiable or diagnosed disability, or has a disability which is less visible. ”

- Challenging the Barriers: Ensuring Access to Education for Children With Special Educational Needs. (YouthLaw Aotearoa, September 2016)

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Introduction

This report is based on our New Zealand youth and their family's experience of life with an Invisible Disability. It has allowed us to pull together multiple resources so that we now present a snapshot of Invisible Disabilities in New Zealand right now! Solely **New Zealand based** research is (and has been up to now) difficult to find so it's not surprising that the disability sector is constantly looking to other countries so we might copy the best of what seems to be working for them. The Invisible Disabilities Cube decided that it was time that New Zealand needed to grab hold of the old "No 8 wire" practice and start the process of finding out and reporting on what is really happening in the NZ landscape. What are we, who work and live within this sector, doing to help ourselves, our clients and their families using what we have here, in New Zealand, right now? It is wonderful that there is currently so much forward planning. We can look forward to expected outcomes in 2020, 2023 or perhaps in 2026 - yet what's happening right now? Who is looking after the children who do not fit into, yet are going through the 'mainstream' systems right now? What about their future?

"The aim of this research was to summarise the available New Zealand based body of knowledge about the lived experience of children and youth with neuro-disabilities and their families that could spur further research to improve their outcomes within a social model framework as well as inform future intervention. Whilst there is a growing body of international research on this topic, our choice was to focus on New Zealand-

based research in the first instance." From the report....

The New Zealand disability sector still relies heavily on overseas content and experience to inform local practice and policy. Case studies and new models of practice are being introduced and monitored, but until we pull together all available New Zealand focused papers and studies, we can't get an accurate view of what is really happening in the sector. Research and investigation are an integral part of any core interest group or organization. Learning from mistakes, identifying possibilities allows everyone the chance to look at what others are doing around us, to help inform our own practice.

By pulling together research that has its roots firmly established in New Zealand soils, we bring you the real state of the invisible disabilities sector report. As an equal partner in this, a section has been given to our youth, who have been, and are still being affected by the policies and processes that have shaped their lives to date. A few of their stories have been included.

Finally we encourage you, the people from the sector (who have similar needs), educators, legal professionals, employers and beyond to contribute and be part of an inspirational and positive movement forward to an inclusive and equal opportunity future. It is our hope that others from the wider sector and all its alliances will join us in our work towards "Let's Work Together".



Invisible Disabilities Collective

*Lets Work
Together!*

The Cube Invisible Disabilities Collective is a group of passionate organisations, who have agreed to place their agendas aside in order to work together to create a new way of delivering disability services across New Zealand.

We believe that no single agency, policy, programme or person can solve the big issues facing the young people in the invisible disabilities sector and that in order to create transformation we need to align or work and our practice.

The Cube Invisible Disabilities Collective

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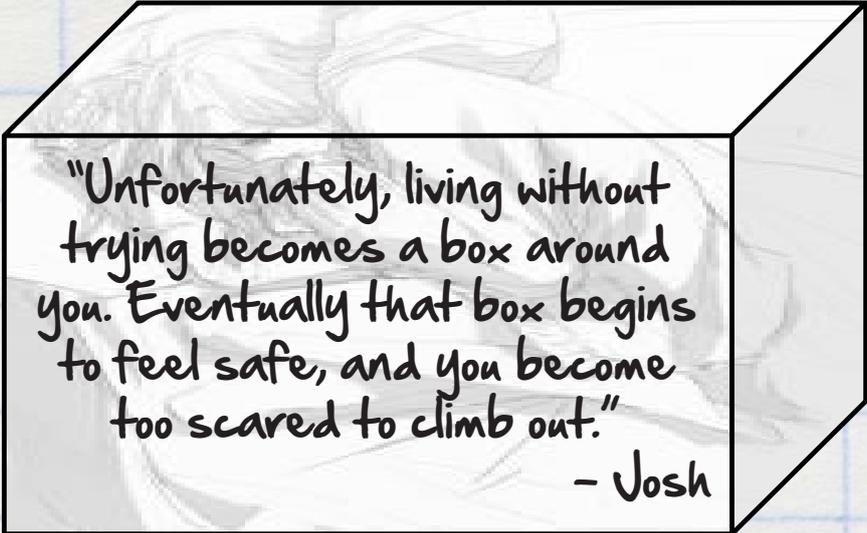


YOUTH ENGAGE MENT GROUP:

Interviews

The Youth Engagement Group (YEG) is a collective of 12 young people aged 16 – 25 who act as consultants for organizations, businesses and even government advocacy panels. This group is comprised of a cross section of young people representing a variety of disabilities, ethnicities and socioeconomic background. The young people have all demonstrated natural leadership abilities and are provided with personal and professional development opportunities and mentoring support. The role of the YEG is to act as Youth Representatives for those who may not have a voice. The YEG developed their own personal development workshops to co-deliver to a new generation of youth leaders in late 2016, with the long term goal of launching youth work and disability staff training as well as mentorship programs based on the philosophy that young people with disabilities are the most qualified to talk about the issues faced by youth with disabilities.

There is more information about the YEG and the work they do later in the report.

A 3D box with a white background and black outline, containing a quote. The box is slightly tilted and has a shadow on the right side. The quote is written in a handwritten style.

"Unfortunately, living without trying becomes a box around you. Eventually that box begins to feel safe, and you become too scared to climb out."

- Josh

Josh's Story:

I'm Josh. I am studying media design at a tertiary institution. For a long time I believed I was dumb and stupid. Nothing but a burden to society. My art was my place to escape. I could shut out the voices and just be me. I never thought my art could be a career for me. I still don't believe I'm good enough to get a job, but I was accepted into media design school so maybe I'm better than I think. I still don't trust my own judgment.

For a long time I was told that I couldn't do things, so I just stopped trying. Over time I put myself in a box. It felt safe; I didn't even try to get out. I ended up staying at home for six months, unemployed, because I couldn't see how I could contribute in society. I started doing things again because I was so bored. It was boredom that broke my lack of self-belief.

I had to make a choice, believe in myself, or give up not have a job. I started to look at the positive attributes I had developed due to my disability. I realised that I can adapt to a lot of different situations and that I can still achieve things even if I'm not considered normal. I identify with the image of the Lion because it reminds me of my own tenacity. I developed this tenacity to climb out of the box and create my life.

Now I live in my own flat with flat mates, I have a girlfriend and I am keeping up with my university commitments. I am also on a youth forum, and I want to make things better for other youth with disabilities. I want them to believe in themselves, to smash down those walls of that box, even if it does feel comfortable and safe. I want young people with disabilities to have support and opportunities, to build meaningful lives for themselves and to give back to society. When I am struggling I focus on my Lion and slowly, one day at a time, I strengthen my tenacity.



Josh's Lion, an image he draws strength from. It represents his **TENACITY** - "My willingness to do anything to get what I need and want"

Tamaras Story: The Youth Ambassador Review

Marble Walls trap the thoughts of those whom think wisely, a mix of history, greed and hope fills the atmosphere of the circled room. Passion overrides the voices before the reality of the situation occurs.

We are all here for similar purposes, even though we end up in opposite directions, because of that history, greed and hope. I saw the education discussion successful, as the community and companies involved are all seeing very similar visions for the future of our education.

The similar views we all shared from my understanding, as an ex-student of the education system with invisible disabilities where, that we need more professional development and better understanding so there is less confusion in the atmosphere, for the teachers to be less stress, so the students do not need to be stress and money is what makes the world turn round, education is what makes our children, country and world grow, I think they go together in a textbook flow but of course it is one of the biggest problems.

With my experience in this system, and with this knowledge of the past year's discussions. My overall understanding on this subject with the public input, is that the education structure needs more heart; by heart I mean understanding, not letting our youth feel left out, widening our horizons to except our new generation of differences into the system, to stop this judgment of mainstream and disability and change the public perspective to except that every living bean is more than label, by changing our education system I think we can just do that, as it is the youth life in till they choose to drop out or finish .

My one statement that I would want to be heard is; our education system structured in 1989 should have been fully re designed to suit our "let's say new type of children" a fair bit ago so it's not a discuss on maybe it should be a discuss on how?

SONIA SPEAKS:

This document is proudly brought to you by “The Cube” Invisible disabilities collective.

This is a first, the first New Zealand only based state of the sector report using research and the voices of young people with invisible disabilities to tell it how it is. Growing up in New Zealand with an invisible disability has some major challenges and multi-faceted solutions.

YES Disability Resource Centre has the privilege of facilitating and playing the backbone role for this forward thinking collective. YES supports the organisations around the table to work together to achieve positive change and give a voice to young people and families who experience invisible disability.

The research contained in the report was collected, analysed and written by Annick Janson and peer reviewed by Anne van Bysterveldt, University of Canterbury; Anita Gibbs, University of Otago; Linda Rowan, Massey University, Trisha Benge, McKenzie Centre and Ruth Gerzon, Inclusion Aotearoa. Finally, Melissa Janson, Behaviour Support Specialist is kindly acknowledged for her support with the research process.

This state of the sector report contains clear recommendations and verbatim stories collected from young people. We saw a gap and a need for uniquely New Zealand based research and therefore the collective commissioned and have been working on this State of the Sector report for a year. We have heard from many parties, professionals, families, providers and people with invisible disabilities that New Zealand needs its own report, and this is it.

We could not have done this without the many voices of young people the volunteer commitment from the organisations and Sue Gould who has co-ordinated and collated the report.

It is a start, and we believe an excellent start, this report has no bias it has not been Government funded or commissioned it is sector driven and delivered, we are proud to share this with you and look forward to seeing you at our conference of New Zealand researchers later in the year.

*Sonia Thursby
CEO,
YES Disability Resource Centre*

YES DISABILITY

YES Disability Resource Centre is a first stop shop for information for the 1 in 4 New Zealanders living with a disability, their family/whanau and caregivers.

We are called YES because in a moment of need people are looking for an answer and we are going to do what New Zealanders are famous for and innovate.

The Invisible Disabilities Cube is one of those Innovations that has been successful. Our work in collaboration and partnership has continued to see YES providing the 'backbone services' the Christchurch Cube and the development of a new Cube in Auckland for Invisible Disabilities. We are proud that the Cube is a unique service, and is currently one of the only collectives in New Zealand that has progressed to delivering intentional action; this area of work is key to the ongoing success of the Cube as we are able

to show real action and real outcomes. The Cube has been presented at many conferences and workshops in New Zealand and has been shared with an organization in Ireland who are now an international partner and are using the Cube framework.

Our young people continually go above and beyond to grow themselves, one another, The Cube and their communities. It's because of them that The Cube exists, but it's also because of them that we've been able to grow in so many interesting and diverse directions.

"Change making happens when people fall in love with a different version of the future." For us, the version of the future we've fallen for is one where all young people have the skills, support and motivation to reach their goals, and we're keen to help other young people reach their potential.

"People with autism and their families seek support and opportunities to manage their own lives so they can participate as citizens in work, community and relationships to their potential."

- Information Gathering for
Autism Workforce across
New Zealand 2015

Report:

THE LIVED
EXPERIENCE OF
INVISIBLE
DISABILITY FOR
CHILDREN,
YOUTH AND
THEIR FAMILIES IN
NEW ZEALAND

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The author wishes to acknowledge the input and feedback from the following peer reviewers: Anne van Bysterveldt, University of Canterbury; Anita Gibbs, University of Otago; Linda Rowan, Massey University, Trisha Benge, McKenzie Centre and Ruth Gerzon, Inclusion Aotearoa. The author also would like to thank Jackie Ede, University of Auckland, for her feedback about the tertiary sector section and the anonymous reviewers from the different sectors referred to in this review. Finally, Melissa Janson, Behaviour Support Specialist is kindly acknowledged for her support with the research process.

This paper is intended to provide a fundamental review of current New Zealand research on the lived experience of children and young adults with neuro-disabilities - sometimes referred to as 'invisible' or 'hidden' disabilities.

This definition includes a wide range of specific neuro-developmental disorders or conditions, which can present as one or all of the following: cognitive delays, communication and coordination difficulties and emotional, social and behavioural problems.

Under the umbrella of The Cube¹, a Collective Impact Framework, our analysis covers developmental, intellectual and learning-based disabilities and communication disorders. Specific to the expertise of the Cube Collective the report has focused on the following primary impairments: Autism Spectrum Disorder - including Aspergers Syndrome, ADHD, Fetal Alcohol Syndrome, dyslexia and dyspraxia.

WHY STUDY INVISIBLE DISABILITIES?

Invisible disabilities create challenges that may be different to those experienced by people with disabilities that clearly manifest themselves. Invisible disabilities can affect a child's efforts to go to school and become a confident learner, a youth's further tertiary studies and professional training, an adult's opportunities to obtain or succeed in the workplace or a person's social life at any age. Neuro-disabilities impact people across their life span starting before or at birth, growing up and growing old. They can impact people's experience with government services, from their first encounter with the health system, to education, social development and justice. The support they need from these services can be very different at each stage. The reality of such 'unseen' disabilities may be hard to recognise or acknowledge for their parents, educators, employers or friends, who cannot see its direct manifestation, or who have not understood how to best support them.

¹ The cube is a Collective impact agency that has commissioned this report on behalf of the Invisible Disabilities Collective. The invisible Disability Collective is made up of ADHD Association, Autism New Zealand, Carabiner Mentoring, Children's Autism Foundation, Dyspraxia New Zealand and Yes Disability Resource Centre. Combined they represent over 6000 families and young people who experience some form of invisible disability. The experience of this collective ranges from lived experience to teachers, strategists, researchers, experienced community development practitioners and business entrepreneurs.

A literature review was conducted to research the experience of people with neuro-disabilities and their families in New Zealand. This review drew on peer-reviewed publications and grey literature to review the factors that contribute to the lived experience of people with an invisible disability. The review adopted a systematic and transparent approach that supports a relatively thorough exploration of the issues and drivers, exploring databases including PsycINFO, ScienceDirect, Emerald and Google Scholar. These were searched using the following search terms: hidden disability/ies, invisible disability/ies, neuro-disabilities, Autism (spectrum, ASD) including Aspergers Syndrome, ADHD, learning disability/ies, learning difficulty/ies, dyslexia, dyspraxia, Fetal Alcohol Syndrome. Additionally, we contacted university or other research based departments/institutions to include research in progress or enquire about related fields we might have overlooked.

These approaches identified a range of publications that were reviewed and selected for inclusion in the review. In total, some 80 documents were reviewed for this publication that either specifically collated data on the lived experiences of children and youth with invisible disabilities and their families in New Zealand, or provided context for it. These are listed in the References section of this report. As the committee carrying out this review did not have expertise in Maori and Pacific People research, this section of the research has not been included in this paper. As this part of the population statistically constitutes a significant proportion of the total of children and youth with invisible disabilities and there might be additional cultural and traditional practices that mask the detection of invisible disabilities, it is important to carry out a similar review within these cultural contexts.

This is a rapid review, in which key sources from the published and grey literature have been examined. Criteria for inclusion in the

review included relevance and insight into the lived experiences of children and youth with invisible disabilities and their families in New Zealand. Provided that methods used in the studies offered quality evidence, specific methodological choices were not used to exclude studies from the review. An example of this might be systematic reviews in health studies often preferring quantitative studies. This is because in studying lived experience, one needs to access rich data largely offered by qualitative studies; additionally, given that this research field is nascent, it would be premature to discard any new information at this stage. The search included reviewing the reference lists of relevant literature sources. The researcher also conducted electronic searches to identify any evaluation reports and policy documents to provide the necessary context within which to describe findings. Finally, the committee advising the researcher asked to consider after careful evaluation, every relevant and robust area of research in the field, hence theses from PhD and Masters students at New Zealand universities found on tertiary databases were reviewed. Studies comparing different types of interventions, or medical or paramedical treatments on these conditions were excluded if they did not inform the lived experience of this group.

The aim of this research was to summarise the available New Zealand based body of knowledge about the lived experience of children and youth with neuro-disabilities and their families that could spur further research to improve their outcomes within a social model framework as well as inform future intervention. Whilst there is a growing body of international research on this topic, our choice was to focus on New Zealand-based research in the first instance.

1. PREVALENCE OF NEURO-DISABILITIES

It is becoming increasingly recognised that visible disabilities have historically overshadowed invisible disabilities within disability studies and the international disability rights movement. This double marginalisation therefore has happened on two levels - within mainstream society and also within the disability community itself (Roman, 2009)². Roman concluded that, from a socio-political perspective, this has diminished opportunities for people with invisible disabilities to participate in productive citizenship. Indeed Lynch (2016) recently stated that “neuro-disabilities have been invisible, but their visibility is slowly increasing” (p. 11). An effort to rectify this situation is underway as invisible disabilities have been recently identified by the United Nations Convention on the Rights of Persons with Disabilities. Including persons with invisible disabilities in society and development was one of 3 chosen themes for the recent 2015 International Day for People with Disabilities³ together with Making cities inclusive and accessible for all and Improving disability data and statistics.

This definition aligns with that of the British Psychological Society (2015), which describes neuro-disability as:

“Childhood neuro-disability occurs when there is a compromise in the central or peripheral nervous systems due to genetic, pre-birth or birth trauma, and/or injury or illness in childhood. This definition includes a wide range of specific neuro-developmental disorders or conditions, with common symptoms including: muscle weakness, communication difficulties, cognitive delays, specific learning disabilities, emotional and behavioural problems and a lack of inhibition regarding inappropriate behaviour.”⁴

The 2013 census showed that 24% of New Zealanders have a disability - a sum of 1.1 million

2 Anecdotal reports of people with Neuro-disabilities facing stigma, discrimination and exclusion, sometimes by other disabled people, are occasionally reported in the media and social media sphere, such as incidents about mobility parking <http://thedailyblog.co.nz/2015/02/01/discrimination-faced-by-those-with-invisible-disabilities>

3 From HRC and United Nations: <https://www.hrc.co.nz/your-rights/people-disabilities/our-work/international-day-persons-disabilities-3-december>

4 Some conditions were not included in the analysis were those which fit either into medical (such as muscle weakness) or Mental Health frameworks.

people. A disability survey was also carried out after the census in 2013 by Statistics New Zealand⁵. In terms of the indicators that Statistics New Zealand collects as part of the national census, it is only possible to aggregate data about individuals who have identified their primary impairment either as an intellectual, speaking, learning, memory impairment or a developmental delay to display results by age. The data relevant to this paper are⁶:

1. Out of all people with disabilities, 18% have an invisible disability (a total of 165,000 people in New Zealand) [total:162,000/1,062,000]

2. Out of all children from 0-14 with a disability, 59% have an invisible disability (a total of 52,000 children) [up to 14yrs: 48,000/95,000]

3. Out of all people from 15 to 44 with a disability, 23% have an invisible disability (a total of 60,000 people) [More specifically, 28% of the 15-27yr old youth with a disability (34,000) have a neuro-disability (121,000)]

Improving data collection about disabled people fulfils one of the key recommendations made by the United Nations Committee on the Rights of Persons with Disabilities and the Independent Monitoring Mechanism in New Zealand (that includes the Office of the

" Because of limitations of New Zealand data, estimates are often used."

- Information Gathering for Autism Workforce across NZ 2015

Ombudsman, the Human Rights Commission and the Convention Coalition Monitoring Group). The Disability Data and Evidence Working Group (DDEWG) was established in June 2015 and is jointly facilitated by the Office for Disability Issues and Statistics New Zealand. The DDEWG aims to define, clarify and prioritize disability information needs relevant to national and international monitoring and reporting and to recommend strategies to address information gaps. This endeavour seeks to identify the life outcomes of disabled people over time and provide Government agencies with the evidence base needed to

5 The Disability Survey was started in 1996, and is conducted after every census. The most recent Disability Survey was conducted in 2013 and aimed to gather information about:

- The prevalence of disability in New Zealand, and how does it vary across key population sub-groups defined on the basis of age-group, sex, and ethnic group?
- The extent to which the social and economic outcomes of disabled people differ from those of non-disabled people, and how do outcomes vary between different groups within the disabled population.
- The extent to which the needs of disabled people are currently being met. It asked what level and type of support do they need to perform everyday activities.
- The factors that facilitate or hinder the participation of disabled people in important life areas (eg learning opportunities, paid work, civic society)
- Identifying who the main carers of disabled people are and what types of support do they provide

The Survey is the most systematic research document about disabilities in New Zealand, and enables comparisons to be drawn about disabled and non-disabled populations and their life outcomes. The aim of the survey was to find out the nature, timeframe, and cause of the disabilities of the population, in order to inform government, community, and disability groups, and other groups which have an interest in the well-being of disabled people. It is also used to advise the New Zealand Disability strategy, monitoring and meeting goals of the UN Convention on the Rights of Persons with Disabilities, and the formation of a health expectancy metric by the Ministry of Health. The Census shows that the total number of disabled people and the disability rate have both increased since the 2011 Disability Survey. The ageing population is expanding, and this increases the likelihood of a disability. The ageing population does not however, account for the overall increase of disabled people.

6 This data is taken from Table 8.01 and 8.02 in the StatisticsNZ spreadsheet on 2013 Disability Survey complemented by a personal communication with StatisticsNZ.

inform decision-making. It is also for New Zealand to report progress against objectives of the NZ Disability Strategy and government obligations under the UN Convention on the Rights of Persons with Disabilities, ratified by New Zealand in 2008.

Statistics New Zealand is keen to clarify what data is needed to develop a shared understanding of how data collection should be prioritised and addressed (Statistics New Zealand, 2006), hence the rationale for the present set of questions. Since children and youth with neuro-disabilities represent a significant proportion of the population with disabilities, the need to understand commonalities and differences between these two groups is clear. Equally obvious though, is that it will only be possible to capture the experience of this group with specific target and intent and that quantitative data will not tell the whole picture. As specified in a list of disability competencies for Health and Disability Advocates (Health and Disability Advocacy, 2008) respectfully interviewing requires using a wide range of data collection angles to make sure people with an invisible disability tell their story in their own voice: “Where possible, let that person tell their own story, in their own way, to the extent they wish...be sensitive to “invisible” disabilities and pick up on signals people send you regarding issues they may have” (p.3) The checklist compiled by the Dyslexia Foundation clearly lists, for instance, methodological issues that would discount researching people with neuro-disabilities only on the basis of questionnaires: one example is “answering yes quickly and frequently to questions” is a “typical well practiced coping strategy to bring an uncomfortable situation to an end” (p. 20). In addition, there are methodological challenges in interviewing children with disabilities that sometimes necessitate thorough thinking about data collection plans (Jensen et al., 2005; Symes, 2004).

CONCLUSION 1: CHILDREN WITH NEURO-DISABILITIES AND THEIR FAMILIES ARE A DISTINCT GROUP, WHOSE CHARACTERISTICS NEED FURTHER STUDY.

The above provide a starting point to understand the extent to which neuro-disabilities are prevalent in the New Zealand population and the rationale to address the specific needs of this large segment of the disabled population. People with invisible disabilities are at risk of being excluded from disability action that addresses some of their more specific needs because they are still unrecognised as a group. If neuro-disabilities remain unrecognised as a group, this is not only an issue for these stakeholders, but it becomes one for service providers who cannot plan services or support clients based on evidence of their needs.

RECOMMENDATION 1: RECOGNISE CHILDREN AND YOUTH WITH NEURO-DISABILITIES/INVISIBLE DISABILITIES AND THEIR FAMILIES AS A STAKEHOLDER GROUP.

Involve this group, contact representative groups and ask for their input to create questions for the next census and co-design other research to collect data that is most relevant and to apply research methods that are most appropriate to this group. Continue detailing what the commonalities amongst people with visible and invisible disabilities are on the one hand, and what are their different experiences and therefore different needs are on the other.

QUESTIONS

1.1 How can future disability data collection be structured so that data can be aggregated to learn more about this stakeholder group?

1.2 How can partnerships be made with the families of children and with youth with neuro-disabilities/invisible disabilities as a stakeholder group? How can families step in and play their part in establishing these partnerships?

1.3 What are the funding implications that unfold from a better understanding of the prevalence and characteristics of neuro-disabilities to support the needs of this group? How can organisations who have expertise

with this group of disabilities be engaged so that these can have real input in research designs, ensuring that the relevant data is collected?

1.4 What knowledge has been collected and what gaps need to be filled regarding the lived experience of children and young adults with neuro-disabilities in Maori and Pacific people communities and their families.



#abilities
#socialchange
#opportunities
#ourfutures



Early Childhood Education

0-4 years

Let's train our Early Childhood teachers to recognise and respond to the needs of all children including those with invisible disabilities.

Let's standardise assessments and create a system that responds quickly to the needs of families and young people.

Let's invest in research and create a better understanding of the invisible disabilities space so that we can create solutions based on evidence.

"something's different with my child"

Johnny isn't like other kids, I can see it when I go to my coffee group. He isn't doing all the things other kids are doing. He doesn't smile or laugh and he isn't hitting his milestones.

I have no idea who to talk to about this, my doctor says to be patient and not all kids develop at the same rate. He has gone to kindy for the first time this week and I didn't want to leave him behind; I don't know what to do.

I need a break because Johnny just doesn't sleep at night and cries a lot. I have gone on a waiting list for him to see a specialist at the hospital but they say it could take up to 4 months for anyone to see him.

What should I do?



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2. EARLY INTERVENTION

Little is known of the point of entry of these families in the Early Intervention system. Early intervention involves a proactive and preventative approach, identifying as soon as possible after birth and in early years those children who may require assistance with communication and language i.e. vulnerable children. It is not a given that families with children with disabilities are listened to in all cases where they come into contact with professionals who should generate early referrals across the sector because of the compounded difficulty of diagnosing some developmental issues early (Alliston, 2007; Bourke, et al., 1999; Cullen & Bevan-Brown, 1999) because of the inherent challenges of identifying at risk populations early enough (Morton & Ataoa Carr, 2014). Hence we know that far from every child with a neuro-disability is seen early, but we don't know how many miss early support opportunities through the system or what their experience is (Lynch, 2016).

Lyons' interviews (2013) of educators, owners and managers of Early Childhood Education Centres (ECEC) shows what educators think about and how they implement inclusion. Lyons' research mentions the gap between what educators say about inclusion and what they do as they referred to children with disabilities as: "blind, deaf, Down syndrome, 'dietary' disabilities, 'not developing as she should be', not normal, IHC, and autistic. Most participants put the disability before the child in their descriptions and the term 'special needs children' resonates throughout the data." (p. 246). Further Lyons' research about educators' knowledge revealed stereotypical labelling, for instance referring to "They're gorgeous and got all that love, but they can sort of bombard other children" about children with Down Syndrome (p. 246). Moreover, they passed judgment on the basis of medical assumptions, e.g. stating that 'A child with a physical disability or a slight mental disability will be easier to handle than one with an emotional or social disability', thus perpetuating a deficit model of disability (p. 246). Most of the mature participants Lyons interviewed had not had formal training about disability, some of the younger educators learned about disability as small parts of their teacher training courses and few overall had recently spent time with

a child with disabilities. Lyons concluded by describing an ECEC manager who stated that she had removed all policies to guide teacher practices for inclusion in the centres for which she is responsible because they single out children with disabilities:

"I absolutely refuse (to have a policy) because I believe that Te Whariki and the... actual licensing criteria is open enough because especially now with the change in regulations and licensing criteria it actually talks about having a program for individual children's needs... "embedded in the discourse is a view of difference as challenging to equality" (p. 246).

The Good Start in Life project, under the Government's Disability Action Plan, seeks to improve the way the system as a whole works for parents, families and whānau with disabled children from 0-8 years old. The project is led by the Ministry of Education in partnership with the Ministry of Health, Ministry of Social Development and ACC. A co-design approach has been adopted, using an evolving methodology, in collaboration with parents, family and whānau, Disabled People Organisations, and Non-Government Organisations. The project is drawing on existing evidence and undertaking original research including:

- A user-led design process, commencing with more than 60 interviews with parents, family and whānau to better understand their journey, experience and perspectives. Taking this information as a starting point, workshops will be held with diverse groups to help generate ideas to further strengthen the things that families value and respond to some of the things families that have experienced to be less helpful.
- Action research to understand what helps or hinders partnership - covering working with families, and with colleagues within teams and organisations, and across providers.

A large body of work underlies both the Ministry of Health and Ministry of Education guidelines for ASD, ADHD, FAS, dyslexia and dyspraxia (Alliston, 2007). These guidelines are based on fundamental research mostly carried out internationally. There is also a significant body of research carried out in New Zealand relating

to diagnosing and interventions for Autism Spectrum Disorder – Including Asperger’s Syndrome, ADHD, Fetal Alcohol Syndrome (FAS), dyslexia and dyspraxia. Having a set of agreed guidelines for professionals to refer to and implement is essential but not necessarily sufficient. The focus of the present paper is in the next level of research – uncovering the lived experience of children growing up with neuro-disabilities and their families, in their encounters with the New Zealand Health, Education and Social Services, in how they experience the support provided by these services and the consequent outcomes of these encounters.

"From a relational perspective a lack of accountability disempowers families within education. Families can become defensive and entrenched in an attitude of distrust when they feel that they have limited agency in the process."

*Challenging the Barriers: Ensuring Access to Education for children With Special Educational Needs.
(YouthLaw Aotearoa, September 2016)*

Qualitative research contributes to inform the question of families’ lived experience in the early stages of life (Janson, 2016; Janson and Davies, 2014) showing that:

- Families raising children with invisible disabilities report encountering difficulties finding help or steering away from ‘deficit approaches’ taken by health and allied health professionals about either their child or themselves; for instance some parents reported that staff interpreted their feelings of overwhelm as grief – the latter impinging on their desire to see progress for their children.
- There are some examples of successful partnerships between families and professionals, but they are sparse and it is difficult to generalise from their experience to make widespread recommendations. Targeted knowledge translation (Davis et al, 2003) is

needed to bridge the gap between empirical knowledge and its application - between what is known to work and what service innovation carried out to support families raising children with neuro-disabilities.

- In a knowledge-poor situation, the role of peers becomes more salient. Many families, however, express the need to move on from traditional advocacy and peer “support” approach, reporting that attending such groups made them, at times, feel worse because there were too many cases where negative participants monopolised the group’s time and attention. Rather, these families wished to build positive leadership with clear group, family and individual outcomes. One way to accelerate change is to design a mechanism for families to share their learning which is more potent, than the imparting of information done by services, thereby creating radically new outcomes for their children. This should be aimed for as early as possible as these families enter the Health and Disability sector. The mechanism that enables such collective capacity building could be aided by mass communication, such as social media; it will reinforce families’ social change movement (Kendrick and Sullivan, 2009) with evidence of leadership building.

BUILDING FAMILY LEADERSHIP

More attention needs to be paid by health professionals to the early experiences of families given that they are the primary – and too often – the only support for their children and youth. There is a paucity of New Zealand based knowledge about the lived experience of children and youth with neuro-disabilities and their families as they interact with the Health system. In 2007 Alliston noted that in spite of clear professional guidelines that refer to working in partnership, it is not clear how this gets done. There is no new research to show this has changed in the past decade. Fowler et al. (2012), describe the Family Partnership Model rolled out by the Royal New Zealand Plunket Society. From the perspective of nursing practice for example the Family Partnership Model involves working with parents in new ways that often don’t easily mesh with existing practices in the sector. The Family Partnership Model stems from the perspective of the professional who is trained to support parents to identify and address problems together. This requires establishing

a relationship different to that of the expert-client one because calling on the expertise of parents involves the professional sharing power with parents and engaging with families on a different level, with “respect, humility and effective communication”. Implementing and sustaining these innovative practices is complex and dependent on organisational supports, professional collaboration and support from leadership. The model can also require more time and resources than traditional expert-client models and is often dependent on individual interpretation of what partnering with families mean. Fowler and colleagues interviewed 22 nurses working with parents, outlining four themes relating to the professional experience of the nurses: evolving practices, exploring with parents, challenging negative constructions and an ongoing commitment to reflecting on practice. Because Fowler et al. did not interview the parents themselves, it is not possible to extrapolate from these results what the experience of parents in this situation was and what different outcomes they would define for their children and themselves.

Knowledge translation (or ‘knowledge to action’) addresses the gap between the knowledge that is collated through scientific enquiry and its application or between what is known and what is actually implemented (Davis et al. 1963). Knowledge translation refers to the activities involved in passing on research from the laboratory or research institute, published in professional journals and presented at academic conferences to people and organisations who can implement it and put it to practical use, often in the public health sector. Translated research is shared with “practical users” either professionals in the health, education, legal or community sectors or end users such as parents. Knowledge translation is not a specific action in and of itself – rather a range of actions (synthesis, dissemination, exchange, ethically sound application of knowledge) targeted at different audiences that vary depending on the research and the time span involved.

Interviews of families of young children with invisible disabilities uncovered the learning pathways that assisted them (Janson, 2015; Janson and Davies, 2014). Whereas the impact of traditional support groups was low, families were able to explain how other structured

learning did make a difference to help organise opportunities for their young children. Families said that information and knowledge from peer stories contributed in ways that complemented established information services in unique ways. That information could be shared via technology, professional coaches and used to contribute to the building of a peer leadership movement – it needs more ‘translation’ to be implemented.

As this paper goes to press, the Government response to the Report by the Education and Science Select Committee, on its inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia and autism spectrum disorders in primary and secondary schools (2017) was published. This report recommends intervening prior to school in order to identify and support children (recommendation 21 to 24).

As detailed by Lynch the cost of this gap in early intervention extends well beyond personal and family levels, emphasising that the return on investment for its cost would have society-wide flow on effects. Research about early intervention for children with neuro-disabilities and their families would inform us on how young person’s can get a better chance to live fulfilling lives, contribute to society and make contributions to their communities through employment. Such research would also inform us on how early intervention could reduce costs for other government services, for instance the justice system (Lynch, 2016).

Consistent with the Government’s Social Investment approach, investing early in building families’ capacity will create significant return on investment. As no such research has been carried out in New Zealand, it is worth mentioning here the results of the extensive review of the social investment value of early intervention carried out by Moore and McDonald (2013) from the world renowned Centre for Community Child Health at The Murdoch Children’s Research Institute and The Royal Children’s Hospital. The authors note that a multi-level, ecological approach, acting on three levels is needed. An effective suite of interventions comprises 1. Programmes and services delivered directly to children and families; 2. Community and service system interventions and 3. Structural/ social level interventions targeting attitudes

and values. This 3 level intervention model is consistent with most of the 2017 Government recommendations⁷.

The added element in Moore and McDonald's review, however, is the role of families in creating better outcomes for their children. Moore and McDonald's analysis concludes:

“The evidence regarding the social benefits of early intervention programs is strong. A number of early intervention programs targeting disadvantaged children and families have demonstrated long-term positive effects such as improved educational achievement and improved overall health” (p.3)

CONCLUSION 2: FAMILY CAPACITY BUILDING IS NECESSARY TO UNDERLIE AND SUPPORT AUTHENTIC PARTNERSHIPS BETWEEN PROFESSIONALS, DECISION MAKERS AND FAMILIES.

Research reviewed above has reported that families in these early stages can be overwhelmed, anxious and disempowered by a system that does not seem to identify or address their needs. Given that families encounter similar issues and challenges, encouraging them to form support peer networks will be of benefit for them to be able to speak in their voice and inform the sector where needed, as organisations for people with disabilities do. There are some examples (see section 6 of this paper) where such groups have formulated their recommendations and the outcomes towards which they wish to work. These families have clearly stated that they want early and ongoing action for their children and that they will fight the obstacles that prevent their children from getting the care and education they need. Given the lack of evidence that professionals have successfully implemented recommendations to form partnerships with families, it is time for the families themselves to take responsibility to understand why forming these partnerships matter and how to do so. These families, then, can be enrolled to reach out to other families in their communities who have not yet been identified by professionals or who have shied away from them.

⁷ Government response to the Report of the Education and Science Select Committee, on its inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia and autism spectrum disorders in primary and secondary schools (2017) Presented to the House of Representatives in accordance with Standing Order 252.

RECOMMENDATION 2: SUPPORT FAMILIES' CAPACITY BUILDING MECHANISMS AND DOCUMENT THEIR IMPACT

QUESTIONS:

2.1 How will the Government decision to intervene earlier than school be implemented and what impact will it have?

2.2 What are the societal experiences of families raising children with neuro-disabilities as children move across their life-span? How does early support for families translate into outcomes for their children and their families? What do successful partnerships between families and professionals look like? Further studies need to add to existing evidence of the parents' and families' impact as they step up in their family leadership roles and act to form new types of partnerships with professionals.

2.3 What mechanisms were activated for the Health and Early Intervention systems to assist parents of, and children, with neuro-disabilities in their early years of life as a result of published guidelines? What outcomes should the Health and Disability sector be accountable for? What outcomes should the Early Intervention sector be accountable for? What pathways for sustainable changes are developed for these families?

3. PRIMARY AND SECONDARY EDUCATION

What do we know about the lived experience of children with invisible disabilities and their families as they move through the education system?

The need to review how big idea changes are actually implemented on the ground is outlined by Rutherford (2009) who described that teachers' interpretations of inclusive education vary drastically. Rutherford takes the example of how teachers and teacher aides collaborate to assist a student with special needs: some teachers do the planning for the student's learning and the teacher aide helps (translated by teacher aide as “helping a child access the curriculum by doing the same

work as peers, but at their level), whereas other teachers don't "take responsibility for teaching all students", leaving teacher aides with the job of adapting the curriculum to the best of their understanding; "the role of aides in these contexts may be interpreted as a pressure valve for teachers, enabling them to get on with their work of teaching "the other 28" students" (p. 97).

Lyons (2013) concludes that "it is unlikely that the legislation and policy for including children with disabilities has transformed the understanding or practices of adults in the long-day sector of ECEC regarding disability and inclusion" (p. 247) rather "merely provided an enlightened rhetoric, which serves to mask the continuation of ableist practices and thinking in the sector (p. 237)". Lyons argues that the concept of inclusion itself has been largely diluted leaving many teachers, owners and managers in ECEC given some language about inclusion and required to practice it, yet making inclusion a reality appears problematic and confusing. This reveals itself in my study in participants' stated beliefs about inclusion that are not aligned with their practices. Inclusive rhetoric provides some absolution, but works to disguise the influence of neoliberal discourse, mask the continuation of ableist practices, and widen a gap between policy and practice in the sector" (p. 247). The aforementioned also applies to children with invisible disabilities, their families and their educators.

The 2016 Special Education Satisfaction Survey did compare parents' and educators' answers to survey questions about their experiences with the education system, but these addressed all disabilities. It reported that an alarming 13% of children with disabilities do not attend school all day; however it did not reveal any further information about the proportion of children with invisible disabilities concerned. Though the survey was not specifically directed at children with invisible disabilities, some data was collected about this group. Covering the Ministry's four special education core services: Early Intervention, Communication, Behaviour and Ongoing Resourcing Scheme (ORS), it addressed an overall sample population of 14,677 children that fitted the criteria:

- a. open/active case,
- b. received over eight hours of service delivery, and
- c. received service in that time period.

This survey showed the usual low response rate of such methodology with 20% of parents and 23% of educators sending back their survey papers, thus drawing a survey sample of 2,550. The researchers oversampled Māori, Pasifika and children receiving behaviour services to increase the number of respondents in these groups and therefore the accuracy of results. Beyond general comments that Special Education Services could improve (providing more services, more one on one time with children and decreasing the wait for services to start following a referral and the waits between meetings, increased at home resources and parent education or filling staffing gaps faster), parents also requested more support and guidance, more tools and strategies for working with their children as well as lowering current age cut-offs. These parents also questioned the urgent support need criteria and some shared that inclusion is not only about funding hours and budget but also about teaching models and smaller classes. The survey findings revealed that parents' (and educators') satisfaction with Special Education Services is at 71% well below the Ministry's target of at least 85% satisfaction for 2015/2016 indicating little improvement in the perceptions of the overall quality of Special Education service delivery since last 2011 survey. Both parents and teachers noted that obtaining services could be made easier ('Had to fight for support') and also reported perceiving uneven service provided by Special Education due to the lack of specialist staff in some areas or because of the differences in styles between individual staff. In addition, parents' expectations of good services before going to Special Education decreased from 67% in 2011 to 60% in 2015.



Junior to Primary

5-7 years

Let's have a plan for children from day one of school.

Let's create a invisible disabilities audit system for schools to use so that they can create environments that respond to the needs of all children attending school.

Let's create a buddy system for all children starting school so that those young people with invisible disabilities are supported and don't feel like they are being singled out.

Hi, Mila started school this week. The whole family was excited and we all went to school to see her off on her first day. By morning tea I got the call to come and get her, she was so distressed and didn't want to be there anymore. She said it was too noisy and too many kids running around and shouting, she said she was scared of going on the playground.

We are working with Miss Sims the teacher to come up with a plan for Mila, we are so lucky to have such a great teacher, she said she felt she needed more training to know how to work with Mila and be able to respond to her needs better.

We have been looking for a course she can go on but can't find anything.



Invisible Disabilities Collective
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Albany



Reflecting on the reasons why 13% of children with disabilities do not attend school all day, the 2016 Special Education Satisfaction Survey respondents agreed on some factors (for instance lack of funding for support hours or child's suspension or exclusion) but disagreed on others. For instance, when it came to explaining why a child did not attend school, only teachers mentioned the child not being ready or unable to cope with all-day attendance, whereas parents did not nominate these as reasons. Other differences of opinion between parents and educators concerned for instance children's opportunities to participate in out of classroom activities with educators perceiving that children have good learning opportunities (77%) whereas parents were less optimistic (61%). A significantly higher number of parents and educators (resp. 97% and 95%) reported that children receiving a Communication service were attending school all day as opposed to those involved in behaviour or Early Intervention service (resp. 82% and 83%).

"They felt that there was no meaningful accountability to ensure that the schools adhered to proper process."

*YouthLaw Aotearoa
September 2015*

Following on from the New Zealand Human Rights Commission 2004/2010 report (p.170) A Right to Education Framework, Kearney (2016) recently listed the issues that parents reported about equality of opportunity and treatment for disabled students and non-disabled students in a study very relevant to students with invisible disabilities. Kearney collected qualitative data from 76 families who came forward having recognised their children's unmet needs. The data might explain some of the aforementioned disagreements between parents and educators and shed further light on parent's view as to the reasons why 13% of the children do not attend school all day (as reported by the Special Education Satisfaction Survey carried out by the Ministry of Education). Parent respondents indicated in 30% of the cases that their children had learning disabilities, 14% identified a need associated

with Aspergers Syndrome, 13% reported behavioural needs, 8% identified speech and/or communication needs, 5% emotional needs, 3% social needs as the main area of needs for children who have experienced these barriers at school. Hence, the respondents in this study had serious concerns about their child with an invisible disability and they represented 63% of the sample. Other disabilities/area of needs included autism, hearing and visual disabilities, representing the remaining 27% of the respondents. Kearney summarized 'availability' and 'accessibility' under the 'rights to education' category on the one hand, 'acceptability' and 'adaptability' under the 'rights in education' category, on the other. Kearney's findings point to parents' identifying significant barriers for New Zealand disabled students:

- 69% of parents identified that their child did not have the same opportunities of a free and compulsory education meeting their child's learning needs as their non-disabled peers had. Issues with funding were reported by 60% of the total sample, the lack of teacher aide or support worker were reported by 56% of the parents and 69% of the parents reported teacher knowledge and 53% teacher attitude as well as 48% reported school principal attitudes as common barriers. These examples included for instance families being asked to pay for teacher aide/support workers hours, parents reporting difficulties with funding application processes or being asked to pick up their child before the end of a school day. Factors associated with teacher knowledge contributed to the most significant barrier with parents reporting their child's teacher use of outdated "deficit models" about teaching and learning, not recognising the unique needs of the children or not taking responsibility for the children's learning.

- 36% of parents perceived that discrimination was not eliminated for their child ("accessibility") for instance with accessing the curriculum, and with being physically separated from their peer group. Parents reported that conditions were being placed on enrolment and full-time attendance at school, for instance with their child only permitted to attend school when teacher aides were present, which often meant taking the child out of school in the later part of the day.

- 39% of parents perceived that their child received an education inferior to that of their peers interpreting the negative climate fostered by their teachers as bullying which was reflected further through verbal or physical abuse by their peers (“acceptability”).

- 40% of parents identified a lack of adaptation to the curriculum, a lack of policies to support authentic inclusion and challenges around the physical learning environment and resources, resulting in lacking the focus on ensuring education responds to the child’s needs and adapts learning stimuli to the learner (“adaptability”).

“Families described being told to keep their children at home in the absence of teacher aide or “support worker “cover”” or situations where their children were only permitted to attend school for part days.”

Challenging the Barriers: Ensuring Access to Education for children With Special Educational Needs. (YouthLaw Aotearoa, September 2016)

The evidence reviewed shows that children with neuro-disabilities grow up feeling increasingly excluded with potentially long-term impact on their self-esteem, experience difficulties to communicate translating into academic failures or into acting out behaviour resulting in being expelled from schools. Lynch listed common characteristics of this group, including “different degrees of comprehension and social (dis)comfort due to low reading age, limited literacy skills, slower cognitive processing speeds and comprehension, impaired or heightened auditory and visual perception, poor short-term memory and variable concentration, reduced ability to understand procedures and follow instructions, inability to comprehend cause and effect and/or consequences. As well as behavioural propensities that can be mistakenly interpreted as hostility, acting out or evidence of guilt.” Neuro-disabilities have been reported to often appear together, compounding risks that children misinterpret instructions or engage in behaviours without fully comprehending their

possible consequences (Lynch 2015, p. 4). An additional caveat to the above data is that it surveyed only families receiving services were surveyed – hence still leaving open questions as to what families and children not currently receiving services are experiencing and what levels of co-morbidity can be reported.

Kearney’s study sheds important light on the experience of children with invisible disabilities and their families (Foster-Cohen and van Bysterveldt, 2016; Gunn, Child, Madden, Purdue, Surtees, Thurlow and Todd, 2004; Healy, 2010; Macartney and Morton, 2009; Turnock et al, 2011). These results further support the experience of YouthLaw Aotearoa’s cases and with other more general inclusion studies (Starr and Janah, 2016). Purdue et al. (2011) for instance, described the barriers that New Zealand children and families face around equitable enrolment and participation in long day Early Childhood Education and the implications this has for the inclusion philosophy: that where children are learning alongside their peers from early on, they will move forward only knowing this as the norm and modelling peer behaviour and learning patters with families expecting these conditions throughout their children’s education pathway. Kearney’s findings are consistent with other research that documented exclusionary thinking and practices in our education system.

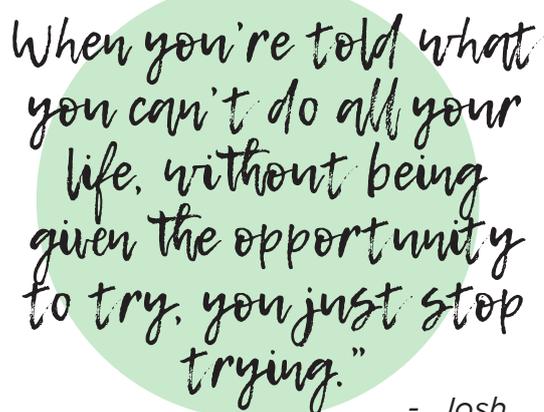
“There is still a large gap between the desired outcome of inclusive education and the provision of support that is required to achieve that.”

Challenging the Barriers: Ensuring Access to Education for children With Special Educational Needs. (YouthLaw Aotearoa, September 2016)

It is no surprise then that when researching the lived experience of the children and youth, some concerning psychosocial challenges are described. Eggleston et al. (2012) for example reported that children and adolescents

diagnosed with dyspraxia not only scored significantly lower in self-esteem with widespread repercussions but that they also perceived their physical appearance, their ability to express ideas (leadership), their evaluation of their social functioning (popularity), their intellectual and school status as lower than those of their peers. The authors reported that children diagnosed with dyspraxia often presented with coexisting learning and mental health conditions, such as dyslexia, anxiety disorder, ADHD or ASD, emphasizing the importance of transdisciplinary input in outlining interests, strengths and difficulties to promote increased competence, occupational engagement and enhanced social participation within this group. Marshall (2005) reported the experience of learning difficulties for primary school students with invisible disabilities as a negative interruption which can narrow their sense of identity as being “learning disabled” and compromise their well-being. Denny et al.’s study (2014) showed that almost one in five high school students report a chronic health condition, including disabilities, which impact on their daily functioning and emotional well-being. The latter study did not differentiate between the types of disabilities that high school students reported; hence it is important to continue developing this field of enquiry. Since the aforementioned barriers presumably did not contribute to students building a positive self-image, it is no surprise that Rutherford (2009) summed up the “student dilemma” barrier as the social cost of teacher-aide support that both students and teacher aides described (“not cool”, “feeling stupid”, “being called dumb by your friends” (p.101)), particularly in high school. Rutherford then questioned whether, in balance, having the educational benefit of a teacher aide was, in fact, worth the academic benefit. Rowan (2010) reported high school students with dyslexia expressing frustration at having been placed into inappropriate in-school remedial reading programs demonstrating their teachers’ lack of understanding of how to assist them. Students explained that they had already understood the principles being taught but that their challenge was to put them into action within the context of the classroom work. Rowan goes on to describe how parents were referred to extra-curricular dyslexia programmes. Additionally, there are some cases where invisible disability, such as dyslexia and dyspraxia do not get revealed until a few

years after children join primary school in the case children have already developed cover-up strategies. Rowan (2010, 2014) notes that it is important for Early Intervention services to enquire about family history of presence of invisible disability/difficulties; in certain cases parents can recognise the presence of traits or experiences from their own experience and so help with diagnosis of dyslexia or other learning difficulties.



When you're told what you can't do all your life, without being given the opportunity to try, you just stop trying."

- Josh

In summary, the available research points to barriers that are systemic, differences in pedagogical approaches with an unknown proportion of educators still using deficit or “sameness as fairness” lenses resulting in students with invisible disabilities not getting on par education opportunities as their peers. They report negative school experiences, including bullying from peers or even teachers. Beyond self-identity and psychosocial costs of feeling misunderstood and devalued, students with invisible disability also experience academic failure and their general wellbeing could be compromised.

What do we know about the systems that support children with invisible disabilities and their families as they move through primary and secondary education?

The 2015 Educational Review Office’s (ERO) report, “Inclusive Practices for Children with Special Needs in Schools” evaluated the education and care of students in schools and early childhood services. ERO reported that 78% of school rated themselves as having an inclusive culture, a positive attitude to including students with special education needs and good relationships with families. Schools reported having developed school-wide systems and practices to put their commitment into action. These included a

strategic approach, a Special Education Needs coordinator (SENCO), a team to coordinate provisions and resources and effective transition processes. Over three quarters of schools in the sample were mostly inclusive, which is an increase from the half reported in 2010. The ERO report states however that: “Progress and achievement data was not always used for self review. Schools were more likely to review how they provided for students with special education needs than how effectively their actions had promoted achievement for these students. Many did not analyse achievement information to identify strategies that were effective for particular groups of students. Reports to the board were also usually about provision of programmes but did not discuss their effectiveness. This means some schools are not well positioned to identify effective practice in teaching or whether resources are being allocated in the most appropriate way (p. 3).” Further to the lack of outcome data for children, no data were collected around the frequency of referrals to SENCOs or development of Individual Education Plans (IEPs) – both crucial mechanisms to identify and address needs and plan service response (The Independent Monitoring Mechanism of the Rights of Persons with Disabilities, 2016).

ERO 2015 noted that “some schools need to improve their use of data about progress and achievement to find out which programmes and teaching strategies are most effective. They also need to share this information with other staff. This process may improve outcomes for these students with special education needs and also identify needs for additional professional learning and development for relevant staff. In the context of a review to understand the lived experience of children with invisible disabilities and their families, a limitation of the 2015 ERO report is its methodological choice to collect self-reports from schools and educators to self-report about their inclusive practice. ERO for instance asked schools questions about “survey[ing] parents about their experience and satisfaction with provisions for their child” (p. 33), without surveying parents about the same questions.

Consequently, Government has made some progress towards its binding obligation to implement the right to inclusive education as laid out by the UNCRPD, by for instance

providing the basic tenets for a philosophy of inclusive education, backed up by educator resources⁸. This was outlined in “The Article 24: The Right to an Inclusive Education Interim Implementation Report” was released in June 2016 by the Independent Monitoring Mechanism (IMM) on the United Nations Convention on the Rights of Persons with Disabilities (“UNCRPD”).

The Ministry of Education have published teaching guidelines for each separate condition, however as Parsonson (2015) notes, whilst commenting about the educational guidelines around FASD he authored, some of these would apply to a range of children with special education needs. For instance each separate set of guidelines to teachers about FASD, ADHD and ASD recommends to talk to the student and consider a learner profile, work with the student’s parents and whanau, discuss assessment data, strategies and support with learning support coordinator and RTLB and access community organisations and Government resources. For each invisible disability, teachers are directed to stakeholder groups that have formed to advocate for the children who have these impairments. Hence, the information as to how to promote inclusion for these children is available and easily accessible: it is on the next level that more progress needs to be done – on the implementation level.

Mitchell (2001) noted new paradigms in the New Zealand special education system are changing, “moving away from categorising students in terms of their disabilities to making judgments on their needs for educational support, from seeing the reasons for failure at school as residing in some defect or inadequacy within the student to seeing it as reflecting a mismatch between individual abilities and environmental opportunities” (p. 333). These new paradigms are consistent with the 2015 ERO report identifying a need to improve teacher capability, particularly in: understanding students with special education needs, strategies for effective inclusion, differentiating the curriculum and ways of monitoring progress within Level 1 of The New Zealand Curriculum. ERO 2015 recommended that “next steps for the Ministry, school leaders, teachers and boards to help ensure all students with special education needs are included and

⁸ See for instance the <http://www.inclusion.tki.govt.nz> website

Transition to Intermediate

8-10 years

Let's have a plan for children from day one of school.

Let's start creating projects with the children at the school to get them to design and deliver actions that help everyone to understand the needs for children with invisible disabilities.

Let's have standards that are monitored for SENCOs and lets provide better training for how to deliver SENCO services.

I think I am wrecking my family.

Hi, Mum and Dad were fighting last night it's cause I got sent out of the classroom again because I swore at the teacher.

I hate it when Mum cries. I hate it when I can't control my feelings. I didn't mean to swear at the teacher but I was angry cause a boy called me a retard!!

I hate this!

Ps. Can you help me feel normal like everyone else?



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Albany



making progress”.

Starr and Janah (2016) noted that despite Government commissioning a series of reports over the past decade about Inclusive Education which have produced numerous recommendations, Government has not publicized what, if any, they have adopted: “it appears that while some recommendations were followed, others were completely ignored” (p. 31) or as noted by the New Zealand Productivity Commission, large stocks of programmes face little review (2015). There have also been a plethora of recommendations from different organisations such as IMM, YouthLaw and researchers about inclusive education.

The IMM report concluded however that disabled children are still facing barriers that prevent them from successfully engaging in education. Starr and Janah (2016) further outlined the IMM concern that “despite drastic policy changes in relation to special education provision, there have been no amendments to the Education Act 1989 in relation to special education for over two decades” (p. 32). Firstly, the IMM notes that the right to an inclusive education is not legislated for, and is not clearly embedded in policy strategies. Secondly, the system is lacking planned coordination and decision-making between disability, education sector groups, such as service providers or stakeholder groups. Thirdly, the IMM encourages the development of a data strategy “specifically designed to assess and monitor inclusive education practices and outcomes. This should include the development of a set of indicators that can be used to measure outcomes against the procedural and structural components of the legislative and policy framework governing the sector” (p. 22).

Consequences of the aforementioned gaps in the Education system are significant: The IMM notes that young people with neuro-disabilities are over-represented in stand downs (14,437 students) and suspension (2692) statistics for disciplinary purposes in 2014:

“Although the Ministry of Education does not report on how many of these students have disabilities, figures obtained in 2009 indicated that, at that time, approximately 40 percent of students subject to formal suspension procedures at school had prior support

from Group Special Education or a specialist learning and behaviour teacher. Relating this to 2014 figures indicates that over 1070 students who were suspended at that time had disabilities. While substantial progress has been made in lowering the overall stand-down and suspension rates, the IMM is concerned that a large proportion of those students (numbering into the thousands) are likely to have learning and behavioural disabilities. The Commission has raised this issue with the Education and Science Committee as part of its submission on the Inquiry on students with dyslexia, dyspraxia and Autism Spectrum Disorder (‘ASD’). Such disabilities come under the umbrella of “neurodisability” which as well as including learning and behavioural difficulties, also includes communication difficulties, cognitive delays, and a lack of inhibition regarding inappropriate behaviour” (p. 16).

According to Starr and Janah (2016): “Despite the change in rhetoric and positive intentions of the Ministry in relation to inclusion, in order for real change to eventuate there needs to be changes in legislation, funding and infrastructure required for a fully inclusive education system. Increasing responsibility has been placed on schools to provide the necessary skills and support to students to enable the capacity and capability to do this. There is still a large gap between the desired outcome of inclusive education and the provision of support that is required to achieve that. The Ministry needs to recognise that significant change requires significant investment” (p. 33).

A parliamentary inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia, and autism spectrum disorders was launched in 2015 with the Education and Science Committee. This enquiry: “1. Identified best educational practice for dyslexic, dyspraxic, and autism spectrum students. 2. Investigated current screening for dyslexia, dyspraxia, and autism spectrum disorders in primary and secondary schools. 3. Investigated support available to and in schools for the transition through education for students with dyslexic, dyspraxic, and autism spectrum disorders, and the adaptations for their learning including Special Assessment Conditions. 4. Investigated whether teacher training and professional development prepare

teachers to identify and support the education of dyslexic, dyspraxic, and autism spectrum students. 5. Reviewed the implementation of the 2008 NZ Autism Spectrum Disorder guideline recommendations specific to education, to assess the level of progress⁹.

CONCLUSION 3: THERE IS INSUFFICIENT EVIDENCE TO CONCLUDE THAT INCLUSIVE EDUCATION IS HAPPENING FOR YOUTH WITH NEURO-DISABILITIES

In conclusion, because children and youth with invisible disabilities and their families form a diverse group, and because such sparse data exists about their lived experiences, it is imperative to address these questions by targeting them as a distinct stakeholder cohort. It is only through the collection and follow up of case specific data that we will be informed about the response of a large system to a very specific needs of each child with invisible disabilities, and the impact of this response on the child's and on the family's further progress. Reviewing the complaints filed with the Ombudsman relating to students with special education needs, surfaces the kind of systemic resistance that children with invisible disabilities and their families face, facing for instance a school Board acting unreasonably in failing to provide access to specialist education resources or procedural flaws in excluding a student (The Independent Monitoring Mechanism of the Rights of Persons with Disabilities, 2016). What is needed to proceed is longitudinal research, starting as early as possible and continuing throughout schooling as well as the translation of research (Davis et al., 2003) that will oversee its implementation.

RECOMMENDATION 3: EVALUATE THE OUTCOMES OF EXISTING RECOMMENDATIONS AND THE FUNDING THAT HAS ALREADY BEEN INVESTED. EVALUATE THE CUMULATIVE IMPACT OF FAMILY LEADERSHIP BUILT IN EARLY INTERVENTION STAGES.

QUESTIONS:

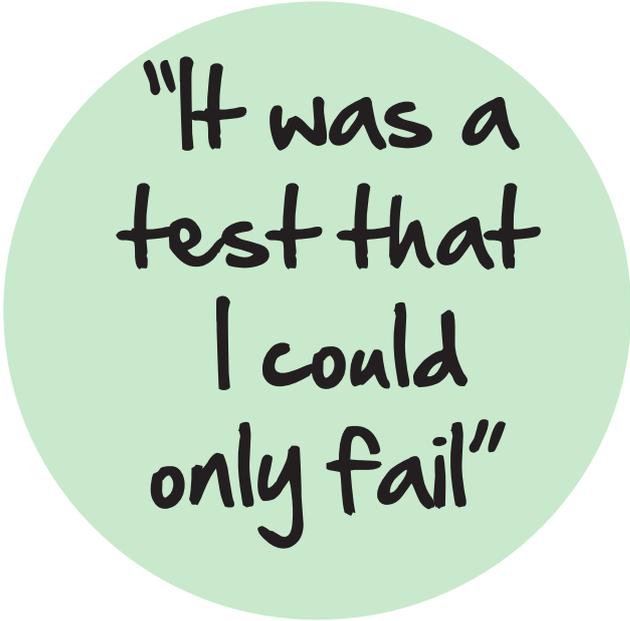
3.1 What are the lived experiences of children and youth with neuro-disabilities as they go

through primary and secondary school?

3.2 How does family support translate into outcomes for their children and their families? What would successful partnerships between families and schools look like? What is the long-term impact of early interventions developing family leadership? How can parents and families contribute form new types of partnerships with schools, as they step up in their family leadership roles?

3.3 What educational pathways and opportunities are developed for children and youth as a result of the specific guidelines put out by Government? What impact do these make on outcomes for children and youth with neuro-disabilities?

3.4 How does the special education research field influence teacher education and ongoing professional development? How does the new knowledge get implemented and what difference does this make?



"It was a test that I could only fail"

*Jason Edgecome,
TEDx - Tauranga, YouTube*

⁹ https://www.parliament.nz/en/pb/sc/make-a-submission/document/51SCES_SCF_00DBSCH_INQ_64710_1/inquiry-into-the-identification-and-support-for-students



Intermediate School

11-12 years

Let's train our teachers better on how to work in the invisible disabilities space. Let's start training during university years and lets expand that training to Work and income workers, SENCOs and other agencies that interface with the invisible disabilities space.

Let's plan with the young people and their families on an education plan for their future.

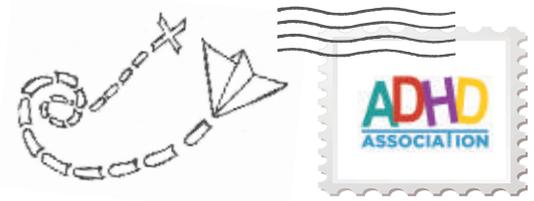
Let's have a school champion in each school, who has direct contact with the Boards of Trustees on how invisible disabilities can be best responded to in each school.

Hi I'm Ollie,
The teachers don't know me and always seem to be really mad.

I never know what I'm supposed to be doing, lots of instructions which make me panic, and by the time I start, everyone else has finished.

I do try hard, but its always wrong.

There's not much point... plus I can't seem to sit still, and have to jump about and yell out I just can't stop myself. So often I just end up sitting outside the principal's office and he tells me off some more!



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Government response to the Report by the Education and Science Select Committee, on its inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia and autism spectrum disorders in primary and secondary schools (2017) accepted 45 out of the 46 recommendations to Government, and offers some explanation on how they will be implemented. Our questions in sections 3.1, 3.3 and 3.4 are in line with the report's following recommendations:

- Setting up systems, policies and guidelines to promote inclusive education (recommendations 4, 7, 11, 31) and assessment procedures (recommendations 28 to 30)
- Offering children more innovative learning environments (recommendation 16), programs targeted to reading (recommendation 26) and communication (recommendation 27)
- Supporting Boards of Trustees (recommendation 3)
- Providing more information and practice guides to teachers (recommendation 3); Supporting teacher formal education and ongoing professional development (recommendations 34, 37, 38 and 39), best practice for inclusion and monitoring through professional development (recommendation 4), promoting a culture of inclusion (recommendations 42 and 43); informing and training other education professionals (recommendations 37-39)

It is, of course, crucial to put in place the very policies and structures that reinforce the outcomes sought. The sector welcomes the Government publishing recommendations and guidelines as to what the different professionals and actors in the system need to consider in their daily roles to create the results needed. As noted throughout the present paper, however, it is on the implementation level that change needs to happen. This is because many such policies, recommendations and guidelines are already in place, as noted in the Government's response above, and even where Government's intent is to widen its scope or expand existing systems, this does not ensure implementation and outcomes.

For the latter, checks, balances and

accountabilities are needed. Whilst these details would not necessarily appear in such high-level documents, as for previous recommendations and guidelines, their impact will need to be systematically reviewed and assessed. The lack of opportunities and inclusion can be blatant for all to see in daily occurrences. Seemingly small details may disappear below the radar. For instance, will these new recommendations, guidelines and systems significantly impact the 13% of children with disabilities that do not attend school all day? Will we understand better how to reach and support children with invisible disabilities out of these 13% and out of all school attendees in general?

Finally, Government suggests providing one clear point of entry for families (recommendation 13), more information to parents through guides (recommendation 8) or through its websites (recommendation 6). Involving families is mentioned only twice in the 2017 Government paper: in recommendation 37 where teachers are urged to "engage with parents" and in recommendation 46 for the Ministries of Health and Education to work in partnership with parents to review the Autism Spectrum Disorder Guidelines. These references to the role of families, however, will not support the necessary system-wide increased engagement with families. For this to materialise, targeted emphasis on families' capacity building, not just on the role of teachers and educators to create these partnerships is crucial.

4. TERTIARY EDUCATION

As students move out of the secondary into the tertiary education system, there is little New Zealand based research to understand how the aforementioned early barriers play out for students with invisible disabilities. The last Ministry of Education government trend profiling survey (2010) about tertiary students with disabilities was carried out in 2009, but did not address the issue of invisible disabilities. It reported that out of all tertiary students, 4.9% self-identified as having a disability, that out of all students studying at level 1 to 3 certificates, only 5.8% and out of all students studying up to level 7 diplomas, only 3.1% self-identified as having a disability. Students with a disability were more likely to be aged 40 years and over (41% of the group with a disability) and only 28% of the group who self-identified with a

disability were aged 18-24.

Complementing the above quantitative data, Rowan (2010) conducted a qualitative study of the learning experiences of four students at a New Zealand university, ranging from 18 to 22 years old. The students who identified as dyslexic retraced how dyslexia affected their past educational pathways, their decisions about their future studies, how they lived the transition into tertiary studies, what their understanding of dyslexia was and how it affected their approach to learning at university. Using a constructivist grounded theory, the study unpacked the participants' experience of discovery and acceptance of dyslexia as well as the extent to which dyslexia affected their learning. Students relate that dyslexia affected their self-confidence and ability to advocate for themselves. They report the extent to which the quality of the supports they had received in high school and how struggling at this earlier stage negatively impacted their aspirations or their concerns about tertiary studies. They connected recognition of dyslexia by themselves and by society to the extent to which they built academic resilience, academic buoyancy, their determination to succeed and the will to become recognised as capable students in spite of the significant barriers they experienced. Working with teachers and tutors that are clear, caring and flexible was a core factor of success.

*Nobody thought
to look at my
environment and
see how it was
affecting my
ability to perform*

*Jason Edgecome,
TEDx - Tauranga, YouTube*

Strategic Thinking Space





Puberty & Adolescence

13-15 years

Let's accommodate the differences with young people, and let's give them a voice on how they can best learn at school.

Let's spend money early in a young person's life to get the best assessments and the best support.

Lets allow youth led innovation to happen in the school systems.

Hi, this is so different, there are only girls here and there are so many of them and they make so much noise all I hear is this endless high pitched shrieking.

To add to this I don't know anybody here, all my other friends went to the local high school and mum thought it would be best I go to a girl's school. I not sure, girls can be mean sometimes.

I hope I make some friends, it took me ages to make friends at my last school, I didn't want to leave. I hope I'm not the weird girl that speaks weird and walks weird and has to have a teacher aide.



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Rowan followed through (2014) by analysing prior educational experiences, decision-making, and first-year experiences of four students at a New Zealand university who self-identified as learning with dyslexia. The study demonstrated that although having reached university entrance requirement, some students may lack the know-how and self-advocacy ability to reach out and enrol for learning supports that are available to them during their tertiary studies. Rowan notes that without relevant and focused course assistance, students with dyslexia incur the risk of being mismatched in academic programs with potential substantial consequences. They may fail to complete the necessary credits to graduate at significant financial costs. On the other hand, providing them with relevant course advice and early access to support services early together with training them in study and time management strategies, these students can achieve better results than the ones they achieved earlier in compulsory education. Rowan concluded that high school academic results should not be used to predict these students' tertiary success. Rowan added that recognising what makes for successful learning experiences of students with dyslexia as they transition to university, can provide us with vital information on how students who had struggled with literacy in their compulsory secondary education can be supported academically to improve on their results during their tertiary education. Wilson and Savery (2013) investigated dyslexia through the discourses that four tertiary students used to describe their learning journeys. Their narrative analysis surfaced five themes: resilience, the positive impact of identification, self-awareness, implementation of compensatory strategies; and, the positive consequences of being open about dyslexia to access existing supports in the learning environment, for example, assistive technologies. The authors identified clear recommendations offered to lecturers on how to make learning easier for students with dyslexia.

Whether the majority of tertiary teachers can identify or even suspect the occurrence of invisible disabilities is still a question, as academics can get to tertiary teaching from a range of backgrounds and would probably

have to enrol in specialised professional development to learn about disabilities, let alone invisible disabilities. Most universities, however, have web pages with information about disability listed. Building on their strong profile within the University of Auckland, Student Learning Centre researchers (Manalo, Ede and Wong-Toi, 2010) offer information and recommendations to their staff on the University website about hidden disabilities.¹⁰ Their research shows that the proportion of students with hidden disabilities in most tertiary environments is quite significant and note that there is a paucity of research in New Zealand exploring how effective learning support can tackle students' poor academic outcomes – even though it is a commonly reported problem. The authors note that much of the research conducted about these students has focused on the nature of hidden disabilities and the extent to which they influence academic results rather than meeting students' learning needs. With the aim of improving results for students with hidden disabilities, this team set out to develop more effective support mechanisms. The majority of students (96%) using the program were identified as having hidden disabilities. The researchers defined 5 categories of Learning Support:

- Metacognitive/executive functioning advice and support (e.g. planning, time management, self-management)
- Cognitive functioning assessment and remedial support (e.g. working on attention, working memory, writing, reading spelling, problem solving)
- Course related instruction and support (e.g. developing skills to address the specific course requirements)
- Institutional environment support (e.g. regarding campus life or the provision of special conditions)
- Personal guidance and support (e.g. in managing emotional issues arising in the course of their studies)

Manalo, Ede and Wong-Toi (2010) then set out to determine how to best address the

10 <https://cdn.auckland.ac.nz/assets/central/about/equal-opportunities/disability-services/awareness-and-teaching-resources/documents/Information%20on%20Invisible%20Disabilities.pdf>

particular challenges faced by students with different types of disabilities. Several indicators suggested that the program is achieving this aim. The increasing number of students (30% compared to a baseline of 15% of returning students) making use of the supports provided by the program shows, among other things, that its support provisions are appropriate and are also viewed this way by students and referring agencies. Finally an analysis of retention and pass rates revealed strong comparability with the general student population. The 93% student retention rate (as determined across semesters) and 89% pass rates closely mapped the university's 2010 overall data for first year students. It appears that these students' hidden disabilities did not become the sole obstacles to their tertiary success. Researchers concluded by reiterating the importance for other universities to invest in the learning support/academic development they provided to their students with invisible disabilities and to carry out ongoing research to understand and improve the impact of these programs.

Students who wish to access the tertiary sector need to negotiate disabilities affecting a variety of cognitive, emotional, communication and social processes. Universities generally provide some supports, but there is too little empirical evidence on their impact. International research (Gibson, 2012; Moraña, 2015) showed that students reported frequent instances where lecturers and other students questioned their condition and the legitimacy of their disabilities because they were not visible. Students' experience 'added insult to injury', in having to supply additional documentation to prove their disabilities with the resulting negative feeling this brought up. The result was that many elected to hide their disability, sometimes only sharing their difficulties with their closest friends or when they needed some adaptation or financial aid (Prowse, 2009; Riddell, Tinklin, and Wilson 2005; Riddell and Weedon, 2014; Viney, 2006).

"It would be good if I was gay, because in university they have a safe place, especially set up for them, and then I could go there when it is all getting too much!"

Research about New Zealand Tertiary students confirmed what international research clearly reported about students with invisible disabilities not wanting to be identified with their disability. As disclosure is voluntary, students may choose not to disclose their invisible disability for a number of reasons: they may fear stigma and discrimination, they may feel uncomfortable about asking for help or may want to get to know a teacher first, they may want to try coping on their own. This has both institutional - impacting performance in student completion and retention - and personal implications - delaying or impairing students' ability to thrive at university (Manalo, Ede and Wong-Toi, 2010) or created a feeling of marginalization for students having to negotiate and (re)construct Invisible Identity in multiple discussions, affecting their positioning towards their peers and their feeling of adequacy (Smith, 2014).

The University of Auckland Learning Disabilities Programme addressed some of the aforementioned barriers as it provided a quarter of its students (25%) with support in building advocacy skills and 18.6% of its students with support in the use of assistive technology. The Manalo, Ede and Wong-Toi (2010) report showed that the program provided wider reaching and longer lasting impact than just special conditions for tests or examinations. The authors explained the significance of the intervention in paving the way for students to develop further study aspirations and independence in learning, which will ultimately enable them to learn the skills to achieve the results they want autonomously. Though the researchers advocated for more research to understand how learning supports can impact students' performance and lived experience, their study is a welcome start to understanding the complexity of these issues and offering actions with potential long term ramifications in addressing the barriers faced by students with invisible disabilities in universities and other tertiary training organisations.

CONCLUSION 4: THERE IS INSUFFICIENT EVIDENCE TO CONCLUDE THAT THE TERTIARY SECTOR PROVIDES ENOUGH EDUCATION OPPORTUNITIES FOR YOUTH WITH NEURO-DISABILITIES

As described above, there is insufficient New Zealand research describing the lived experience of students with invisible disabilities

in university to draw any conclusions about their lives as tertiary students (Rowan, 2014) and the extent to which they achieve their potential by studying. However given the low numbers of enrolments of students with disabilities, it is likely that there are both barriers to enrolment and obstacles to thrive for students with disabilities, both visible and invisible. New Zealand universities need to offer adequate assistance for students to learn, including those with invisible disabilities. The Kia Orite, Achieving Equity: The New Zealand Code of Practice for an Inclusive Tertiary Education Environment for Students with Impairments document (Tertiary Education Commission, 2004) currently under review translates a clear set of parameters that tertiary institutions need to take into consideration when addressing the needs of their students with disabilities, but without further specific research, it is not possible to evaluate the extent to which students with invisible disabilities are supported in ways that make a difference to access, enrolment and academic success.

RECOMMENDATION 4: EVALUATE THE GAPS AND OPPORTUNITIES FOR STUDENTS WITH INVISIBLE DISABILITIES IN TERTIARY EDUCATION AND PROFESSIONAL TRAINING

4.1 What is the lived experience of youth with invisible disabilities as they prepare for and enter the tertiary education system?

4.2 What supports are available to them across the board and what difference do these make?

5. PROFESSIONAL TRAINING AND EMPLOYMENT

Jensen et al. (2005) showed that 23% of unemployed disabled people aged 18-64 have learning and intellectual disabilities and though a proportion of them can get part time work, the impact of their disability is statistically higher in them obtaining full time employment. These statistics however, were not fully aggregated by primary disability with data tables showing 25% of people with “other disability” which may include our target research of youth with neuro-disabilities.

The little qualitative research that was carried out clearly contrasted what young New Zealanders with intellectual disability want (further education and training in a tertiary environment, work experience and paid employment, living and relationships, feeling integrated in their community) to what they got (limited opportunities in tertiary education and pathways, in employment, in social networking, in living conditions and sense of community).¹¹

Milner and Paris (2013) reported case studies on youth looking for open employment and emphasised the dichotomy between what these young people want to and feel they can contribute and how many of them actually end up feeling that their strengths are underused or that they can only get low paying jobs. These authors reviewed the changing policies around employment and disability and added to their research details of seven stories of young people with intellectual disability. Some of these young people describe career aspirations far higher than the ones offered to them, for instance some describe only being offered cleaning jobs whereas they were hoping for professional challenges; however since they needed the income, they had to accept these offers: “No one has been there [business name] as long as I have ... but it is the same job as I was doing when I started”. Milner and Paris outlined the importance of positive professional experiences, such as those offered by workplace training experiences in developing self-confidence and friendships that lead to shared activities after work. However, although innovative workplace training demonstrated that many could indeed learn to take up more responsibilities such as leading a team and supporting peers, most were not able to get jobs that matched their aspirations of professional success, flatting, driver license, car or home ownership.

Dealing with the gap between expectations and reality (Gladstone, 2014) concluded that there is a need to research practical solutions that embody policy - otherwise the latter remains rhetorical:

¹¹ Broadstock (2012) published the comprehensive New Zealand Autism Spectrum Disorder Guideline supplementary paper on supported employment services, based on international research, hence its findings are not included in the present review.

“The clear voice of the young people with learning disability in our study demonstrates that their transition experiences do not provide them with the life they say they want. They do not enter tertiary study that leads to paid employment and have limited involvement in the wider community. They appear to remain mostly at the margins of society as a commodity traded by the special education and social welfare industries”
(p. 336).



#disability
#inclusion
#respect
#action



Transition to Leaving 16-21 years

Without support and youth led plans of action, our young people may not make it this far.

Let's work together across government, social services and the people that are affected by invisible disabilities to ensure transformation happens in our schools and communities.

Hi, school is not a highlight of my life. I may seem like a rebel to my friends and teachers, I do like learning, I learnt the periodic table when I was 9, I love science, writing and learning new skills but at school I don't learn anything.

I simply just cannot stand being in the same room with a teacher that thinks she knows me but just makes me stressed, the endless dramas about who's dating who and people laughing at me for my ideas in class. It just feels like everything about me is been pulled apart and destroyed because I am not the same as everyone else.



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Disability disclosure has been shown by international researchers to be a significant stressor for people with invisible disabilities. The latter face at least two major dilemmas: coping with the challenge embedded in detecting and accepting a disability, on the one hand and thereafter taking the decision of whether to disclose the invisible disability during a job interview or in their existing workplace, on the other (Clair, Beatty and MacLean, 2005). This follows on from the double irony identified by Nelissen et al. (2014) that disclosing an invisible disability may harm an employee because of unclear legal protection. International authors have gone as far as referring to people weighing up the risks against potential benefits of “coming out” (Valle et al. 2010) thus drawing similarities with the identity experience of the LGBT community. These authors studied the narratives of special education teachers who self-identified as having an invisible disability to explore the complex, ongoing issues that “disability disclosure” raises - even paradoxically in educational environments.

The State Sector has designed policy, taken initiative to collect more meaningful data in the work sector and is playing a lead role in employing disabled people to respond to obstacles identified¹² and to “give the public confidence that the State Sector understands, and is responsive to, the needs of its diverse citizens” (Hawker, 2016). New Zealand research has outlined employers’ attitudes as obstacles to workers with a disability (Cleland and Smith, 2010; Te Pou, 2013; Woodley and Metzger, 2012) but more research is needed to understand the impact of these on people with neuro-disabilities and the implications of the State Sector latest initiatives for this group.¹³

As opposed to the experiences of this group with open employment, the different work reality afforded by entrepreneurship may offer a different type of experience. Interviews

of young adults who had transitioned from school into next stages reported that flexibility of their funding did allow these young people more control. Individualised Funding, for instance made a significant difference in the lives of youth with neuro-disabilities because their families were able to steer their lives where their interests lay and help them shape their own success rather than trying to fit in with uncompromising organisations and institutions (Janson, 2015). Such successes then materialised as, for instance, families helping youth with neuro-disabilities create their own business shaped around their passion and talent. More research needs to be carried out however to understand how to increase participation rates and sustainability of both self-employment and open employment actions. Self-employment may not have been the first option for these young people, however open employment options may have proven inaccessible to them for factors beyond their control with some of them never even getting their first job interview. With flexible funding, youth may invest these resources to understand and build on their strengths. It is to be noted however that, as for many other disability instances, the flexibility of funding sometimes resides not in its ‘big picture’ descriptions but in the small details of how it is administered, so careful consideration has to be applied at the implementation stages.



“I feel lucky to have had the support to find my talent and passion, and to create a job out of that.” - Janir

¹² <https://www.hrc.co.nz/your-rights/people-disabilities/more-info/#the-employment-problem>

¹³ One such example is EmployAbility [<https://www.workandincome.govt.nz/employers/employ-disabled-people-or-people-with-health-condition/index.html> link valid as at 26 January 2017]. The Ministry of Education is the lead agency for a Disability Action Plan Project, aimed to improve transitions from school and tertiary education to employment. Called “Pathways to Employment” this is a cross-government project, and will be undertaken in collaboration with young disabled people, their families, Disabled Person’s Organisations, Non-Government Organisations, educators, service providers and employers.

Working from the evidence that we do have¹⁴, we know that by the time they reach employment age, a significant proportion of youth with neuro-disabilities are so disenfranchised that as noted by Lynch (2015) they may “prefer to be known as a ‘criminal’ rather than ‘dyslexic’ because of the social stigma attached to neuro-disabilities. The author advocates that change is needed if this proportion of our young people prefers to face prison than wear this label or that they do not grasp the implications of their actions: “We must not label young persons, we must offer them hope” (p. 11). “It is estimated that 80% of young people in the Youth Court have at some point been subject to a Child, Youth and Family (CYF) notification. It is likely that, in many of these cases, family circumstances are underpinned or compounded by neuro-disabilities. (Lynch, 2016, p. 4) The implications of children and youth facing repeated academic and professional failures and disappointments capped with stigma are very serious given that neuro-disabilities are over-represented in the New Zealand youth justice system.

“In our experience, despite understanding the connection between certain disabilities such as Autism Spectrum Disorder and their corresponding emotional and behavioural symptoms; schools can still perceive this kind of behaviour as disobedience rather than attributing it to the student’s individual needs.”

Challenging the Barriers: Ensuring Access to Education for Children With Special Educational Needs. (YouthLaw Aotearoa, September 2016) Pg35 P2

CONCLUSION 5: THERE IS INSUFFICIENT EVIDENCE TO EVALUATE THE PATHWAYS AVAILABLE TO YOUTH WITH NEURO-DISABILITIES TO ACCESS MEANINGFUL EMPLOYMENT

When do neuro-disabilities get counted? How will we identify the characteristics of the employment experiences of youth with neuro-disabilities – the challenges but also the strengths that can form a base for action to improve their employment outcomes? Because of the obstacles faced throughout their life-span, youth with neuro-disabilities are particularly vulnerable in the justice system because their comprehension of the criminal process is different and that without making adjustments and targeting explanation to their communication capacity, young offenders may disengage from the process (Pierse-O’Byrne, 2014). Lynch (2016) noted that “in line with overseas research, communication disorders alone could affect 60-90% young offenders” (p.7). Targeted research can outline those practices that do make a positive difference to them, identify the specific strengths displayed by youth with neuro-disabilities and further embed these into action plans.

RECOMMENDATION 5: EVALUATE THE GAPS AND OPPORTUNITIES FOR YOUTH WITH INVISIBLE DISABILITIES AS THEY PREPARE TO ENTER THE WORKFORCE

- 5.1 What is the lived experience of youth with invisible disabilities as they prepare for and enter the workplace?
- 5.2 What are the types of employment that youth with invisible disabilities get? Do these tap into their potential and what they can and want to contribute?
- 5.3 How can we identify gaps and opportunities for these young people?

¹⁴ Other research such as Cleland and Smith (2010) is not specifically reviewed in this paper because it did not focus on youth with neuro-disabilities, though pointing to similar need for wide action, from implementing best practice as early as age 14 for transition from school, to creating work experience, employment and community participation programmes for all youth with disabilities.

6. THE FASD TAKING ACTION STAKEHOLDER GROUP: SELF ORGANISING FOR CHANGE

“FASD is lifelong and often it is an invisible disability. A person with FASD will need support throughout each stage of their lives” (Fetal Alcohol Network NZ).

The Fetal Alcohol Spectrum Disorder – Care Action Network (FASD-CAN), a North Island national initiative and the Dunedin FASD group, a local grassroots organisation have worked to create change for people living with FASD. These networks have collated available research as well as orchestrated data collection through a variety of qualitative and quantitative research methods – ranging from auto-ethnography and anthropology to quantitative methods. Rogan and Crawford (2013) further describe the development of a Community of Care through a series of collaborations, which took place between diverse group of professionals across disciplines aimed at improving diagnosis and treatment of FASD in New Zealand.

These groups have taken responsibility for disseminating research results to varied stakeholders, from parent support groups to professionals and lobbied with government to take action on its findings. Some examples are Symes (2004) using such seminars to disseminate information to multiple audiences. Symes posits that action must start “from the top and work down to the grassroots population”. She received “extensive positive feedback from the audiences, identifying this as an important way of educating communities and agencies on FASD, its implications dealing with any negative stereotypes and assumptions associated with FASD. More community focused presentations need to be carried out to ensure increasing awareness is happening within the general population” (p. 202).

A RANGE OF METHODOLOGIES TO UNCOVER DIFFERENT KNOWLEDGE

Researchers have used a range of experimental methodologies to understand the experience of FASD families. Rogan and Crawford (2013) for instance described the historical unfolding whereby different organisations got involved to monitor the different facets of the

disability – from pre-natal alcohol exposure, to evaluating the social cost of more general alcohol abuse. To gather evidence through their caregivers about the issues faced daily by FASD individuals and their caregivers with New Zealand professionals, Symes (2004) used medical anthropology. Gibbs (2016) combines her professional and lived experiences through auto-ethnography. Setting out to focus specifically on the lived experiences of New Zealanders with FASD, Salmon and Buetow (2012) used mixed method designs to carry out a comprehensive review to find out the challenges these individuals face on a daily basis. In order to capture the experiences and perceptions of these participants, qualitative methodologies were used. Parsonson (2014) carried out a comprehensive international review of FASD in the educational sector, to provide guidelines for teaching children with FASD. Finally, Easton, Burd, Rehm and Popova (2016) used economic models and a counterfactual scenario method (representing a situation where FASD is prevented) sought to quantify the impact of FASD in the workplace by estimating the productivity losses associated with FASD in New Zealand.

The experience of people living with FASD shows that they are affected throughout their life span (Symes, 2004; Salmon, 2008; Salmon and Bluetow, 2011; Bagley, 2013, Parsonson, 2014, Gibbs, 2016, Easton et al., 2016, FASD Working Group, 2016) as described in the following sections.

EARLY INTERVENTION

The 1990’s presented somewhat of a conundrum in relation to the inability to diagnose FASD. The prevalence of FASD was unknown and there was no capacity to identify the disability. This perceived low prevalence in turn resulted in a dearth of support services, a classic ‘catch 22’ (Rogan and Crawford, 2013). In 2004 Symes noted:

“For many the journey in search of a diagnosis for New Zealand children is both difficult and in some cases inaccessible. Without diagnosis there are no interventions to reduce the occurrence of serious secondary disabilities. This situation requires an urgent government review. Education surrounding FASD needs to come about from the Ministry of Health” (p. 201)

These challenges were also noted to have significant repercussions, for instance those pertaining to placement issues:

“New Zealand [lacks] agency professionals that fully understood the ramifications and implications that the FASD client can have on existing policy and procedures, and how inappropriate many of these policies are when used on this group of people and their caregivers. Procedures surrounding suspected FASD or diagnosed FASD individuals within individual agency systems need to be drafted and implemented to assure safety of both caregivers and the FASD person. All agency workers need to have a solid understanding of the issues surrounding FASD and in particular the limitations it presents to those directly affected. It is no longer acceptable in this time of public accountability (particularly social service agencies) to place a FASD child with a family that have no idea that the child is diagnosed as FASD and/or have no training in regard to FASD ... FASD individuals often appear far more capable than they actually are and adults can present themselves well. Often even with a diagnosis of FASD they are placed by income agencies in inappropriate job positions, purely because of the lack of knowledge surrounding this disability” (Symes, 2004; p. 202).

Symes carries on to state that because strategies to facilitate behavioural management were not discussed, this often resulted in successions of placement disasters compromising the personal safety of either the child or other family members:

“It is no longer acceptable that FASD children are adopted out into the community without the prospective parents being informed about the medical problem affecting the new baby. International repercussions for agencies that have continued to adopt out FASD children to unsuspecting parents are beginning to appear in the Canadian newspapers. Agencies are being held accountable and in several cases in America, being sued for this covert practice” (p. 202)

Even following initial medical diagnosis, there were no services to address the social, personal, family and behavioural problems, all of which impact directly on the individual's ability to attain and sustain independent living,

and the families' ability to cope. *“Professionals must listen and take into account the expert information given by caregivers, acknowledge - not marginalize - its content”* (Symes, p. 209).

Rogan and Crawford (2013) noted the early role of Maori leadership which recognised negative effects of fetal exposure to alcohol during pregnancy as early as 1874); “our babies are not born healthy because the parents drink to excess and the child suffers” and submitted their concerns to government (Petition of Haimona te Aotearangi and 167 Others to the House of Representatives, 1874). The authors recall how the first official diagnosis of FASD in New Zealand did not occur until 1996 and how collaborations worked to increase supports for FASD-affected children and families, resulting in a main group of skilled clinicians that could train other professionals working across District Health Boards. A Developmental Assessment Program (DAP) was developed specifically for FASD in order to meet community needs and upskill families and children affected by FASD. The DAP team then refined their procedures to two stages; screening and information gathering, and definitive transdisciplinary assessments. The implications of this process are that greater accuracy is reached in diagnosis, enabling practitioners to make referrals to the DAP team. Highlighting the importance of sharing knowledge across disciplines, the DAP group recommends future directions which individual cases are supported, knowledge is shared, and consultation is requisite. The authors conclude that though the process of developing New Zealand diagnostic capacity has been challenging, it was also positive.

EDUCATION

Researchers have converged to describe FASD-related impact at school. Salmon and Buetow (2012) report adults remembering being perceived and treated as ‘different’, enduring bullying, struggling with attention in the classroom and issues such as unfinished schoolwork escalating into conflict with teachers. These challenges left them feeling insecure and describing a low self-esteem.

After becoming aware in 2014, that the Ministry of Education were developing a resource supporting FASD, members of the FASD-CAN committee met with the Ministry to make sure

that the experience of New Zealand families living with FASD was represented in any national document. The Ministry of Education commissioned Barry Parsonson to research the topic (2015) and his recommendation was summarised in an 8-point guidelines for teaching children with FASD, which he also noted would apply to most children with disabilities. *“These strategies represent some important best practice points derived from experience in teaching children with FASD and include elements of teaching practice that work well with a range of children with special education needs. Each strategy is important and more likely to be effective when used in combination with others”* (p: 17-19). The Ministry of Education launched their new online FASD Guide for Teachers¹⁵ in August 2016, as part of the Te Kete Ipurangi (TKI) resource for teachers to raise awareness amongst teachers on how to work with these students. Key themes can be applied to other invisible disabilities:

1. Create structure in a flexible environment
2. Support participation and build confidence
3. Present information to support understanding
4. Support students processing and organisation skills
5. Provide support and options for students to create, learn, and collaborate
6. Manage successful transitions

YOUTH

Even when a diagnosis is given, children and young people have difficulty to understanding, identifying with, and talking about their own FASD. Gibbs (2016) discusses how other young people view their disability and construct their FASD identity in everyday and social spaces. Aiming to teach young people with FASD empowering ways to voice their experiences with the disability, Gibbs (2016) emphasised passing on a positive voice for her children to talk about FASD. The results of the research were that her own children learnt to discuss their disability in this positive way. Gibbs concluded that more research which aims to

lead young people to find their voice in relation to FASD needs to take place.

Salmon and Buetow (2012) added mental health as another significant issue, including impulsive thoughts, problem drinking, and suicide ideation and attempts. Memory problems were prevalent, from forgetting appointments to repeating mistakes over their lifetime. Socialisation problems ranging from difficulty in making and keeping friendships, loneliness, and being treated as ‘different’; *“People don’t realize that I have stuff going on with me until I’ve told them and it’s changed their perception of me totally! Then they don’t want anything to do with me. It’s almost like they think it’s contagious”*.

EMPLOYMENT

Challenges in the workplace have been described by a number of authors. Salmon and Buetow (2012) view these as an extension from school challenges: *“If I work more than 15 hours, I lose it. Then I get fired”*. Other participants reported discrimination from peers and employees based on a criminal conviction; *“...passed the drug test, got eight weeks into the job and then they found out that I had a criminal record”*; they said, *“Your work ethics good, your work is top-notch but we can’t keep you on”*.

Easton, Burd, Rehm and Popova (2016) translated aggregated productivity losses as ranging from \$NZ49 million to \$NZ200 million for 2013 alone. This figure represents 0.03% to 0.09% of the annual gross domestic product in New Zealand. *“These costs represent estimates for lost productivity attributable to FASD and do not include additional costs incurred by governmental and private entities including social costs, such as both higher costs and or less effective spending by the education, health and justice systems”*. (p. 72)

Adding to widespread societal impacts Symes (2004) outlines significant individual and family consequences:

“If a person is fired from that job due to poor performance, which is highly likely, he/she will automatically (by legislation) be placed on a stand down for eligibility for an unemployment

¹⁵ <http://inclusive.tki.org.nz/guides/fasd>

grant. This is a common situation for my participants with adult FASD children and youth. The family will be seriously affected, as they will have to provide for and financially support their FASD child until they qualify for the unemployment benefit or be directed to yet another inappropriate job. New guidelines need to be created for agency personnel to follow, ensuring the safety of agency workers from external criticism and accountability.”

INVOLVEMENT WITH JUSTICE

Salmon and Buetow (2011) pointed to involvement with the law and authority, some of which happened while still in school; *“I got done for shoplifting in a school uniform”*. Many participants rejected their disability diagnosis, but with time, some came to further understand the indicators and symptoms, and accepted it. Some made suggestions on how to improve the lives of others with FASD. The researchers conclude that bettering the lives of these individuals can be achieved by increased education across health, social, educational, criminal, and policy contexts, of the issues people with FASD and their families encounter.

GROWING SOCIETAL AWARENESS THROUGH POLITICAL INFLUENCE

The Fetal Alcohol Spectrum Disorder – Care Action Network (FASD-CAN) has achieved much progress in lobbying government for change. Rogan and Crawford’s article (2013) further illustrates how collaboration across communities resulted in knowledge to advocate and support the creation of multidisciplinary diagnostic services for FASD in New Zealand. The above evidence shows the importance for a range of professionals to gain knowledge about FASD – from health and social agencies, through educational and criminal justice officials, through to policy makers and the complex issues that individual with this disability and their families report.

In August 2016, the FASD Action Plan was inaugurated in parliament. It asserts the vision that people who have FASD and their whanau/family “live the best possible lives”. The role of the FASD action plan is viewed as vital to provide resources, support and diagnosis. The plan has 5 action points about preventing FASD and another 5 about improving services

to people with FASD, the latter summarised below as most relevant to the present paper:

1. Improve the capacity of frontline staff to diagnose FASD and respond with empathy to those with FASD and other neuro-disabilities.
2. Improve the capacity of clinicians to diagnose FASD.
3. Better the transdisciplinary collaborations of professionals working with significant neuro-disabilities and their capacity to provide high quality assessments.
4. Design focused, coordinated and consistent pathways for assisting people and their whanau/families and caregivers to access support.
5. Carry out research into the occurrence of FASD and other neuro-disabilities in New Zealand.

CONCLUSION

Significant barriers have been identified throughout the childhood and youth of people with neuro-disabilities: inequity in access to services and education, repeated experiences of failure some starting at very young ages and yawning gaps between aspirations and professional opportunities. Moreover, children and their families have had to endure rampant discrimination due to uninformed societal attitudes. By definition, many will not ‘see’ an invisible disability and therefore do not believe or empathise with their life experience. This has flow on impacts on youth identity, some learning to conceal their difficulties, rather than face negative attitudes or stigma, and thereby leading to a new level of challenge and potential failure.

Secondly, there is a dearth of consistency in policy implementation resulting in a lack of clear pathways to follow for youth, families or service providers. How recommendations and guidelines are implemented is under question. Stace (2007) for example, points to the lack of follow up on the 2008 New Zealand best practice guideline around Autism Spectrum Disorder, released along with \$17.5 million to fund the implementation of the 300 recommendations it made. What has the impact of this investment been? A remaining

question coming out of this study pertains to what factors have been hindering progress? Stace further adds that many of these recommendations are basic human rights to education, building independent living and access to recreation and employment – and this stands for the recommendations around other neuro-disabilities. Beyond the rhetoric, more research needs to be carried out to verify if and where guidelines are being adopted and whether outcomes are achieved for children and youth with neuro-disabilities and their families.

Thirdly, some new thinking can be developed extrapolating from lessons learnt from other movements who have created unique bodies of knowledge around their quest. For instance, the “universal design” field has emerged to provide solutions to the specific challenges of people with physical disabilities. Lynch (2015) expressed: “just as you wouldn’t expect a person in a wheelchair to run a marathon; you shouldn’t expect a person with communication difficulties to understand the complex language and concepts of our justice system. Just as we adapt buildings to allow people with physical disabilities to move around in their daily lives, we should adapt the procedures and parameters of our justice system to facilitate those who have difficulties with communication and comprehension” (p. 3). The ideal to pursue is to educate early intervention professionals, front staff, educators and employers about the different communication styles, and the strengths of those with invisible disabilities with whom they come into contact. Is it possible to advocate for social justice and to seek to rectify the current situation to an even playing field? For people with neuro-disabilities, the outcomes from the UN Convention for People with Disability may not translate as the protection they deserve. We could in fact ask ourselves if

the situation is not worse now for people with neuro-disabilities, because some organisations and authorities may feel that they have acted to protect disabled people by having ticked off physical accessibility boxes. How aware are policy makers about the need to plan and design systems for non-physical access such as the many communication challenges that people with invisible disabilities face?¹⁶

Fourthly, stakeholders coming together to build momentum is a positive step forward. Given that it is not clear how guidelines recommending that organisations make special efforts to create meaningful partnerships with families have been applied, it is necessary for families to raise that bar and play their role in creating new paths for collaborations. Families can build the self-confidence and impetus needed to approach organisations to form these partnerships. “While we know that great partnership practice does occur, it seems that it is not widespread. We need to research the factors that contribute to or inhibit good partnership practice and find ways to ensure that effective partnering is embedded in all our practice” (Carpinter, 2016). Partnerships between people with neuro-disabilities, their families and professionals across the board would create new expectations and better outcomes for these stakeholders. This is no small outcome to ask from some professionals, and just as with the earlier ideas of professionals forming authentic partnerships with families, this would require changes in relationships, with some professionals relinquishing some of the power that tends to come until now with expertise (Allred, 2015).

Recommendations 2.2 and 3.2 in the present paper to support and strengthen family leadership, especially starting early will, according to the best available evidence, have a positive return on investment. This could

¹⁶ Recent accessibility assessments are offered to organisations so that their customers may be informed in advance of how their special needs may be taken into consideration. Some of these assessments include accessibility features to accommodate people with “Learning and Intellectual impairments” or for whom English is not their first language (<http://www.beaccessible.org.nz/be-welcome>). Assessments specify that information about the organisation is provided in legible print or banners for those who find it difficult to read and understand information, however it is not clear how organisations offer better communication experiences to, for instance, customers on the Autistic spectrum.

Government response to the Report of the Education and Science Select Committee, on its inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia and autism spectrum disorders in primary and secondary schools (2017) Presented to the House of Representatives in accordance with Standing Order 252.

provide the grounds for a powerful inter-ministerial collaboration, since significant resources from Health, Education and Social Development are involved over the life span of children with invisible disabilities. Empowering parents early with information and a sense of positive agency over their children's progress will have a "domino effect" throughout their children's life. For instance, parents who will have experienced the results of positive partnerships with professionals in the first years of their children's lives will have understood the potential hidden in such partnerships and will want to build on them. Parent leaders may then join their schools' Board of Trustees and see their role as positive catalysts in educating these fora where needed. Recommendations and guidelines alone cannot create the kind of social change needed – only action can. Without positive experiences of identifying children needing additional supports and the experience to troubleshoot issues that are bound to arise, a Board of Trustees will remain unaware of the need to implement change or unable to do so.

Family leaders will ensure that not only those students at their schools will undergo positive schooling experiences; they will act as catalysts to create learning events around issues that are troubleshoot and resolved. These cumulated positive experiences will strengthen implementation around a culture of inclusion in these schools – with a momentum that can build and spread throughout the country.

However, together with supporting such leadership development programmes, longitudinal research would need to be carried out to identify and analyse these long-term impacts so that relevant adaptation can be integrated to better understand and increase these impacts over time. It is important therefore, for Government to add to their research programme (recommendations 17, 18, 19 and 20)¹⁷ a strand integrating families 'leaning in' and building their capacity to contribute to reaching better outcomes for children with invisible disabilities. Continuing to invest only in professionals and educators in the hope that they reverse past trends and create future

better quality partnerships with families will not result in real change – (doing more of the same won't lead to different results) the time has come for families to step up and take up leadership roles in creating these partnerships. This point is important because as noted throughout the paper, improved outcomes for children and youth with invisible disabilities are not only dependent on policies, systems and guidelines, but on promoting different **implementation** – and in this regard, parents partnering with professionals can create new impact.

The overarching trends reviewed above point to barriers impairing the well-being and experiences of people with invisible disabilities as family members, pupils, students and employees, throughout their life span. Reflecting why sectors such as health, education, social development, and justice have only moderately served children and youth with invisible disabilities or failed to build partnerships and collaborations with their families is vital for the effort to create necessary change.

¹⁷ Government response to the Report of the Education and Science Select Committee, on its inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia and autism spectrum disorders in primary and secondary schools (2017) Presented to the House of Representatives in accordance with Standing Order 252.

REFERENCES

- Alliston, L. (2007) Principles and practices in early intervention: A literature review for the Ministry of Education. Research New Zealand.
- Allread, K. (2015) Engaging parents of students with disabilities: Moving beyond the grief model. *Improving Schools*. 18(1): 46-55.
- Armstrong, H. M (2014) Inclusion Through Different Eyes. M.A. Thesis, Available from: http://mro.massey.ac.nz/bitstream/handle/10179/6626/02_whole.pdf?sequence=2&isAllowed=y
- Bagley, K. (2013) Fetal alcohol spectrum disorder diagnosis and intervention: An investigation of professional practice in New Zealand (Doctoral dissertation, University of Otago).
- British Psychological Society (2015) Children and Young People with Neurodisabilities in the Criminal Justice System. Position Paper. Available at: http://www.bps.org.uk/system/files/Public%20files/cyp_with_neurodisabilities_in_the_cjs.pdf
- Broadstock, M. (2012) New Zealand Autism Spectrum Disorder Guideline supplementary paper on supported employment services. Wellington: New Zealand Guidelines Group.
- Carpinter, A. (2016) Personal communication.
- Clair, J. A., Beatty, J. E. and MacLean, T. L. (2005) Out of sight but not out of mind: Managing invisible social identities in the workplace. *Academy of Management Review*. 30: 78-95.
- Cleland, G. and Smith, A. (2010) Journey to work: Creating pathways for young disabled people in New Zealand. Discussion Document Prepared for CCS Disability Action and Workbridge. Christchurch, New Zealand: Creative Solutions Disability Consultancy.
- Davis D, Evans M, Jadad A, Perrier L, Rath D, Ryan D, Strauss, S. Rappolt, S. Wowk, M and Zwarenstein. M. (2003) The case for knowledge translation: Shortening the journey from evidence to effect. *BMJ*, 327: 33-35.
- Denny, S., de Silva, M., Fleming, T., Clark, T., Merry, S., Ameratunga, S., Milfont, T. Farrant, B. & Fortune, S. A. (2014) The prevalence of chronic health conditions impacting on daily functioning and the association with emotional well-being among a national sample of high school students. *Journal of Adolescent Health*. 54(4): 410-415.
- Easton, B., Burd, L., Sarnocinska-Hart, A., Jürgen and Popova, S. (2014) Productivity losses because of morbidity attributable to fetal alcohol spectrum disorder in Canada: a demographic approach. *Journal of studies on alcohol and drugs*, 75(6): 1011-1017.
- Education Review Office, Inclusive practices for students with special needs in schools, March 2015, Available at: <http://www.ero.govt.nz/publications/inclusive-practices-for-students-with-special-education-needs-in-schools>
- Eggleston, M., Hanger, N., Frampton, C., and Watkins, W. (2012) Coordination Difficulties and Self-Esteem: A Review and Findings from a New Zealand Survey. *Australian Occupational Therapy Journal*. 59(6): 456-462.
- FASD Working Group (2016) Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019: An Action Plan. Wellington: Ministry of Health.
- Foster-Cohen, S. H. and van Bysterveldt, A. K. (2016) Early Childhood Inclusion in Aotearoa New Zealand. *Infants and Young Children*. 29(3): 214-222.
- Fowler, C., Rossiter, C., Bigsby, M., Hopwood, N., Lee, A. and Dunston, R. (2012) Working in partnership with parents: the experience and challenge of practice innovation in child and family health nursing. *Journal of clinical nursing*, (21-22): 3306-3314.
- Gibbs, A. (2016) The impact of Fetal Alcohol Spectrum Disorder (FASD) on the family: Are there ways to make it less painful? Paper presented at the Redefining Family Conference (13-14 Jan), Auckland, New Zealand.
- Gibson, S. (2012) "Narrative Accounts of University Education: Socio-cultural Perspectives of Students with Disabilities." *Disability and Society* 27 (3): 353-369.
- Gladstone, C. (2014) The Search for a Good

- Life: Young People with Learning Disability and the Transition from School. PhD Thesis, University of Canterbury, Christchurch: Available at: http://ir.canterbury.ac.nz/bitstream/handle/10092/9640/thesis_fulltext.pdf?sequence=1&isAllowed=y
- Guerin, A. P. (2008) "It's the Small Things that Count: Making Sense of Working in a Partnership to Support the Inclusion of a Child with Autism Spectrum Disorder". MTL thesis, University of Canterbury, Christchurch: Available at: http://ir.canterbury.ac.nz/bitstream/10092/1847/1/thesis_fulltext.pdf
- Government response to the Report of the Education and Science Select Committee, on its inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia and autism spectrum disorders in primary and secondary schools (2017) Presented to the House of Representatives in accordance with Standing Order 252. Available at: https://www.parliament.nz/en/pb/papers-presented/current-papers/document/PAP_72401/government-response-to-report-of-the-education-and-science
- Hawker, A. (2016) Lead Toolkit for Employing Disabled People in the State Sector. Ministry of Social Development. Wellington. Available at: <https://www.ssc.govt.nz/sites/all/files/lead-toolkit.docx>
- Healey, D. (2010) The treatment of Attention-deficit/Hyperactivity Disorder: Where are we at and where are we going? *Journal of the New Zealand College of Clinical Psychologists*, 20(3): 25-28.
- Health and Disability Advocacy (2008) Disability Competencies for Health and Disability Advocates. Wellington. Available at: <http://advocacy.hdc.org.nz/media/186224/disability%20competencies%20for%20health%20and%20disability%20advocates.pdf>
- Ho, R. and Jacquemard, R. (2009) Maternal alcohol use before and during pregnancy among women in Taranaki, New Zealand. *New Zealand Medical Journal* 122(1306): 20-9.
- Janson, A. and Davies, B. (2014) E-Peer support to build leadership in the disability sector. Centre for Applied Disability Research (CADR) Inaugural Conference (27-28 May), Sydney, Australia.
- Janson, A. (2015) Stories that build leadership in the disability sector. Presented at: Claiming Citizenship Conference (15-17 Oct), Vancouver, Canada. Available at: www.incharge.org.nz/?page_id=1377
- Jensen, J., Sathiyandra, S., Rochford, M., Jones, D., Krishnan, V. and McLeod, K. (2005) Work Participation Among People with Disabilities: Does the Type of Disability Influence the Outcome? *Social Policy Journal of New Zealand*. 24: 134-159.
- Kearney, A. (2016) The right to education: What is happening for disabled students in New Zealand? *Disability Studies Quarterly*, 36. Available at: <http://dsq-sds.org/article/view/4278/4217> http://www.incharge.org.nz/?page_id=1377
- Kendrick, M. J. and Sullivan, L. (2009) Appraising the leadership challenges of social inclusion. *The International Journal of Leadership in Public Services*. 5: 67-75.
- Lynch, N. (2016) Neurodisability in the Youth Justice System in New Zealand: How Vulnerability Intersects with Justice. Proceedings from the 2016 Neurodisabilities Forum (Wellington, 2016).
- Lyons, L. (2013) Transformed Understanding or Enlightened Ableism? The Gap Between Policy and Practice for Children with Disabilities in Aotearoa New Zealand. *IJEC*, 45: 237-249.
- Lyons, L. (2011) The 'business' of disability: tensions, responsibilities and challenges in a market model of early childhood education and care. *The First Years, Nga Tau Tuatahi. New Zealand Journal of Infant and Toddler Education*, 13(1): 29-33.
- Lyons, L. (2005) A place for everybody? Challenges in providing inclusive education for children with disability in Aotearoa/New Zealand. *The First Years: Nga Tau Tuatahi. New Zealand Journal of Infant and Toddler Education*, 7(1): 16-20.
- Macartney, B. (2008) Disabled by the discourse: Some impacts of normalising mechanisms in education and society on the

lives of disabled children and their families. *New Zealand Research in Early Childhood Education*, 11: 33-50.

Mallard S, Connor J. and Houghton L. (2013) Maternal factors associated with heavy periconceptional alcohol intake and drinking following pregnancy recognition: a post-partum survey of New Zealand women. *Drug and Alcohol Review* 32: 389-97.

Manalo, E. Ede, J. and Wong-Toi, G. (2010) Provision of learning support for university students with learning, mental health, and other forms of hidden disabilities. *The Open Rehabilitation Journal*. 3: 23-33.

Marshall, S. A. (2005) What's it like being us: stories of young New Zealanders who experience difficulty learning (Doctoral dissertation, Auckland University of Technology).

Milner, P. and Paris, A. (2013) *Work Partnerships that Work: A Review of the Disability Related Employment Literature*. Beasley Institute, Dunedin.

Ministry of Education Tertiary Sector Performance Analysis and Reporting (2010) *Profile & Trends 2009: New Zealand's Tertiary Education Sector*. Short paper on Students with Disabilities. Retrieved from: <http://www.educationcounts.govt.nz/publications/series/2531/99259/short-articles>

Ministry of Education (2016) *Special Education Satisfaction Survey*. Retrieved from: www.educationcounts.govt.nz/publications/special_education/client-satisfaction-survey

Ministries of Health and Education. 2016. *New Zealand Autism Spectrum Disorder Guideline*. Wellington: Ministry of Health. Retrieved from: <http://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline>

Mitchell, D. (2001) Paradigm shifts in and around special education in New Zealand. *Cambridge Journal of Education*. 31(3): 319-335.

Moffat, T. K. (2011). *Inclusion in Early Childhood settings in Aotearoa/New Zealand* (Master's thesis, Massey University, Massey, New Zealand). Retrieved from: <http://www.massey.ac.nz>

[ac.nz/massey/research/library/library_home.cfm](http://www.massey.ac.nz/massey/research/library/library_home.cfm)

Moriña, A. (2017): 'We aren't heroes, we're survivors': Higher education as an opportunity for students with disabilities to reinvent an identity, *Journal of Further and Higher Education*, 41(2): 215-226.

Morton, S. and Atatoa Carr, P. E. (2014) *Growing Up in New Zealand Vulnerability Report 1: Exploring the Definition of Vulnerability for Children in their First 1000 Days*. Growing Up in New Zealand. Available at: <http://www.growingup.co.nz/en/research-findings-impact/research-publications.html>

Moore, T.G. and McDonald, M. (2013) *Acting Early, Changing Lives: How prevention and early action saves money and improves wellbeing*. Prepared for The Benevolent Society. Parkville, Victoria: Centre for Community Child Health, The Murdoch Childrens Research Institute & The Royal Children's Hospital.

Nelissen, P. T. J. H., Vornholt, K., Van Ruitenbeek, G. M. C., Hülshager, U. R. and Uitdewilligen, S. (2014) Disclosure or nondisclosure- Is this the question? *Industrial and Organisational Psychology*, 7(2), 231-235. Retrieved from <http://doi.wiley.com/10.1111/iops.12138>

Newell, C. (2009) Studying with a Disability or Chronic Illness. In: Denholm, C. and Evans, T. (Eds). *Doctorates Downunder: Keys to Successful Doctoral Study in Australia and New Zealand*. Camberwell, Vic.: ACER Press, 2006: 129-135. Retrieved from: <http://search.informit.com.au/>

New Zealand Human Rights Commission (2010) *A Right to Education Framework*. Wellington.

New Zealand Productivity Commission (2015) *More Effective Social Services*. Wellington.

Parsonson, B.S. (2015) *Fetal Alcohol Spectrum Disorder: Strategies for Learning, Behaviour and Communication*. Ministry of Education, Wellington. Retrieved from: <http://www.inclusive.tki.org.nz/assets/inclusive-education/MOE-publications/Barry-Parsonson-Revision-06-07-15.pdf>

- Pierse-O'Byrne, K. (2014) Identifying and Responding to Neurodisability in Young Offenders. LLB (Hons.) Dissertation, University of Auckland.
- Purdue, K., Gordon-Burns, D., Rarere-Briggs, B., Stark, R. and Turnock, K. (2011) The exclusion of children with disabilities in early childhood education in New Zealand: Issues and implications for inclusion. *Australasian Journal of Early Childhood*, 36(2): 95-103.
- Prowse, S. (2009) Institutional Construction of Disabled Students. *Journal of Higher Education Policy and Management* 31(1): 89-96.
- Research New Zealand (2014) Insights from Women about Drinking Alcohol During Pregnancy: A qualitative research report. Wellington: Health Promotion Agency.
- Riddell, S., and E. Weedon (2014) Disabled Students in Higher Education: Discourses of Disability and the negotiation of Identity. *International Journal of Educational Research* 63: 38-46.
- Rivalland, C. and Nuttall, J. (2010) Sameness as fairness: Early childhood professional negotiating multiculturalism in childcare. *Early Childhood Folio*, 14(1): 28-32.
- Rogan, C. and Crawford, A. (2013) Building a Community of Care through FASD Diagnosis in Aotearoa New Zealand. In Carpenter, B., Blackburn, C. and Egerton, J. [Eds] (2013). *Fetal Alcohol Spectrum Disorder: Interdisciplinary perspectives*. Routledge, UK: 174-183.
- Roman, L. G. (2009) Go figure! Public pedagogies, invisible impairments and the performative paradoxes of visibility as veracity. *International Journal of Inclusive Education*, 13(7): 677-698.
- Rowan, L. M. (2010) Learning with dyslexia in secondary school in New Zealand: What can we learn from students' past experiences? *Australian Journal of Learning Disabilities*. 10(1): 71-80.
- Rowan, L. M. (2010) It's not all Black and White: The transition of students with dyslexia into the first year of university study. M.Ed. Thesis (Massey). Retrieved from: http://mro.massey.ac.nz/bitstream/handle/10179/2221/02_whole.pdf?sequence=1
- Rowan, L. (2014). University transition experiences of four students with dyslexia in New Zealand. *Australian Journal of Learning Difficulties*, 19(2), 1129-1136.
- Salmon, J. V. (2008). Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences. *Canadian Journal of Clinical Pharmacology*, 15(2): 191-213.
- Salmon, J. V. and Buetow, S. A. (2011) An exploration of the experiences and perspectives of New Zealanders with fetal alcohol spectrum disorder. *Journal of Population Therapeutics and Clinical Pharmacology*, 19(1): 41-50.
- Salmon, J. V. and Buetow, S. A. (2012) Transcendental phenomenology and classic grounded theory as mixed data collection methods in a study exploring fetal alcohol spectrum disorder in New Zealand. *Journal of Population Therapeutics and Clinical Pharmacology*. 20(2): 82-90.
- Selvaraj, J. (2015) Inclusive education in New Zealand: Policies, politics and contradictions. *International Journal of Inclusive Education*, 19(1): 86-101.
- Smith, K. (2014) What's your kryptonite? In/visible disability identity construction. Language and Society Conference. The University of Waikato. <http://www.waikato.ac.nz/fass/conference/langsoc/LANGSOC-Abstracts.pdf>
- Stace, H. (2007) The long unfinished journey towards human rights for disabled people in Aotearoa New Zealand. *Human Rights Research* (5): 1-13. Retrieved from: <http://www.victoria.ac.nz/law/centres/nzcpl/publications/human-rights-research-journal/publications/vol-5/PAPER-1-Human-rights-and-disabilities-Hilary-Stace.pdf>
- Statistics New Zealand (2016) Enduring Questions in the Disability Domain. Wellington.
- Statistics New Zealand (2013) Disabilities and Labour Market. Wellington. Retrieved from: <http://www.stats.govt.nz/~media/Statistics/browse-categories/health/disabilities/disability-and-labour-market/disability-and-labour-market.pdf>

Statistics New Zealand (2013) Disability Survey. Wellington. Retrieved from: http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx

Starr, K. and Janah, N. (2016) Challenging the Barriers: Ensuring Access to Education for Children with Special Educational Needs. YouthLaw Aotearoa. Retrieved from: <http://www.youthlaw.co.nz/wp-content/uploads/Challenging-the-Barriers.pdf>

Symes, M. M. (2004) The legacy of prenatal exposure to alcohol: Fetal Alcohol Spectrum Disorder, the New Zealand situation: a thesis presented in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Social Anthropology at Massey University, Albany, New Zealand.

Te Pou o Te Whakaaro Nui (2013) The employment of Disabled People in Disability Support Services – Research Report. The National Centre of Mental Health Research, Information and Workforce Development. Auckland: New Zealand.

Tertiary Education Commission, New Zealand Ministry of Education (2004) Kia Orite, Achieving Equity: The New Zealand Code of Practice for an Inclusive Tertiary Education Environment for Students with Impairments. Wellington. Retrieved from: <https://www.fmhshub.auckland.ac.nz/4/3/files/kiaorite-codeofpractice-1.pdf>

The Independent Monitoring Mechanism of the Rights of Persons with Disabilities (2016) Article 24: The Right to an Inclusive

Education. Retrieved from: https://www.hrc.co.nz/files/5814/6758/2123/IMM_Interim_Implementation_Report_final.pdf

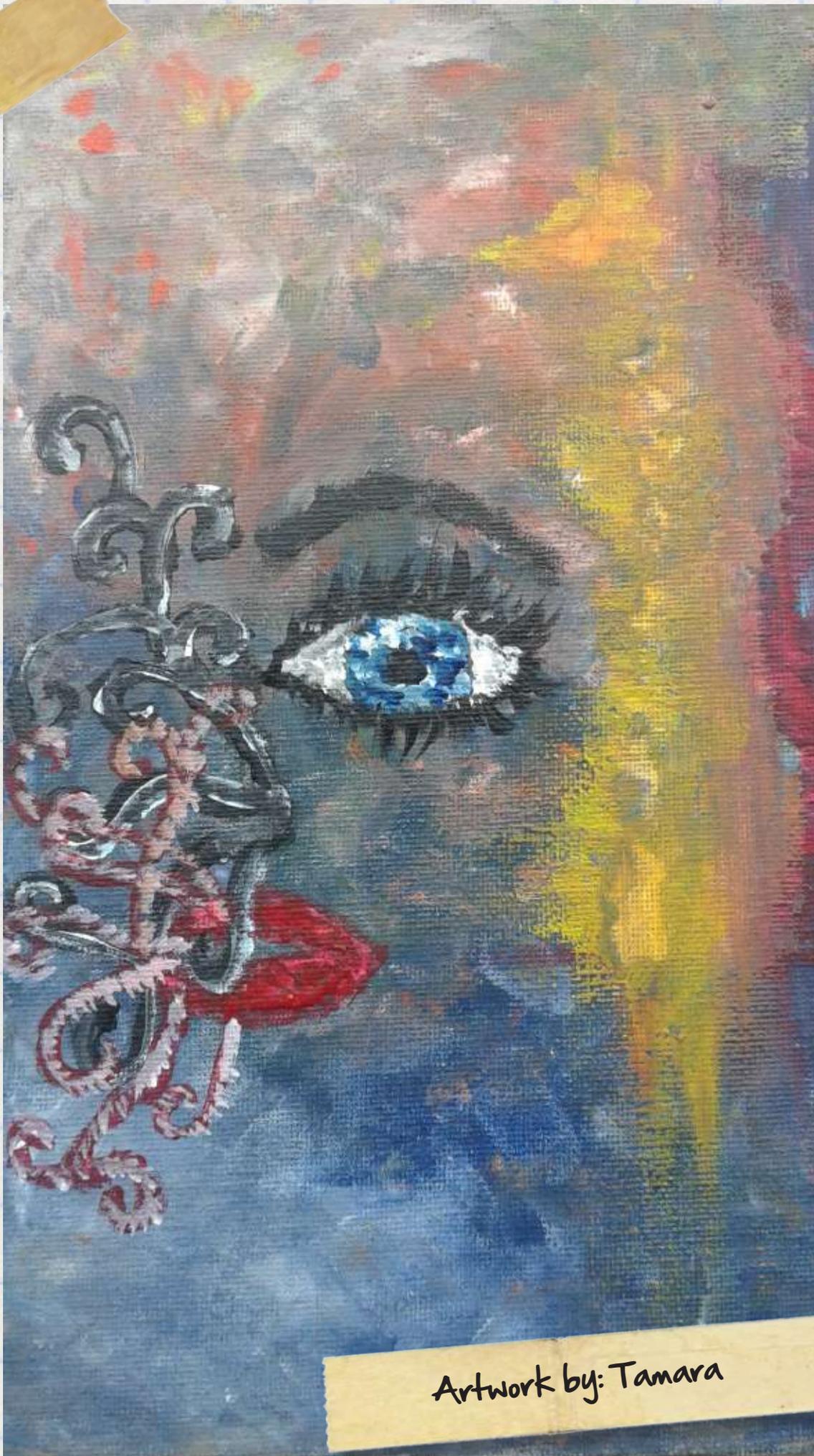
Turnock, K., Gordon-Burns, D. Purdue, K.; Rarere-Briggs, B. and Stark, R. (2011) “I’m scared of that baby”: How adults and environments contribute to children’s positive or negative understandings and experiences of disability in early childhood settings [online]. New Zealand Research in Early Childhood Education, (14): 23-37. Retrieved from: <http://search.informit.com.au/>

Valle, J. W., Solis, S., Volpitta, D. and Connor, D. J. (2004) The Disability Closet: Teachers with Learning Disabilities Evaluate the Risks and Benefits of “Coming Out”. Equity and Excellence in Education, 37: 4-17.

Wilson, M. and Savery, N. (2012). Stories of resilience: Learning from adult students’ experiences of studying with dyslexia in tertiary education. Journal of adult learning Aotearoa New Zealand, 40(1), 110-123.

Woodley, A. and Metzger, N. (2012) Employer attitudes towards employing disabled people, Ministry of Social Development: Wellington.

Wouldes T. (2009) What Health Professionals Know and Do About Alcohol and Other Drug Use During Pregnancy. A Research Report in Collaboration with Alcohol Healthwatch. Auckland: University of Auckland.



Artwork by: Tamara



REPORTS
FROM
THE
SECTOR



Freedom
Art by
Yaniv Janson

In my work with children between the ages of 11 and 15 (mainly boys) with ADHD who are struggling at school, I've found certain common issues. These children will have been brought to me by their mothers to work with them in the capacity of ADHD coach.

Some of the issues shared by these children:

- ▶ They are usually quite intelligent however struggle to keep up with assignments and often need extra time to think and digest new information. Conversely, they may think very quickly and the classroom pace may be too slow or boring.
- ▶ Children with ADHD are expected to act as if they do not have ADHD even when it is known that they do. In other words, while diagnoses may or may not lead to taking prescription medication, it seldom leads to changes in the work load, learning modality or behavioural expectations of the child that might be helpful and appropriate.
- ▶ ADHD is likely to be accompanied by other learning challenges such as Dyslexia. While the ADHD may be picked up, the Dyslexia may not, therefore those issues will persist even if the child is taking medication for the ADHD.
- ▶ Students with ADHD often experience a disconnection with school based learning. They become doubtful regarding their ability to learn and may have given up, no longer seeing the point of trying.
- ▶ These children can be somewhat delayed in maturity in some aspects while being more mature than their peers in other respects. For example while children with ADHD may seem more immature in some social contexts, they often have an advanced ability to feel compassion and empathy for others. (Unless ADHD is accompanied by high functioning Autism which might negatively affect their ability to relate to others)
- ▶ These students often feel that their ADHD makes them a target for bullying and will react to defend themselves from that sense of danger in various, not always helpful ways.
- ▶ A drive to use video games like Minecraft, that can appear to border on obsession, is often seen with these children suggesting that this kind of game offers their brains a type of cognitive gratification. This type of non-violent, creative and social game playing is not necessarily to be discouraged, but may require some adult imposed time structure.
- ▶ These children want to do well but don't usually have a grasp of the best strategies that would support their achievement. They will sometimes develop strategies on their own that are less than helpful. For example, a child with ADHD may be talkative in class in order to support his attentiveness.
- ▶ In cases of the children I have met I have the impression that their teachers had a limited understanding of what ADHD is and how it may affect their student with ADHD's ability to perform and behave. In each instance, the teacher expectation seemed to be that the child needed to work out for him or herself how to manage their ADHD. At the Primary and Intermediate level, this is fundamentally unfair.

With a relatively small amount of additional knowledge about ADHD, a teacher is in a better position to, with a slight shift in attitude and approach; ease the learning process for the child with ADHD and also to support the student's understanding of themselves. With understanding and being allowed a voice to advocate for themselves, students can and will work out remarkably well, what they need to do to achieve, despite ADHD challenges.



REPORT PREPARED BY TONY HANNE, GP

ADHD was first described very convincingly in 1798, although it had different names in those days. The general agreement is that the frequency of ADHD is about 5% in all ethnic groups. It is now well recognised as being a lifelong problem. A good proportion learn somewhere in adult life to manage it well enough not to need treatment. There is clear evidence of physical differences in the brains of those with ADHD.

The social effects of this disorder are huge. Adults with ADHD have 4 times as many accidents as the rest of the population and have a 25% greater chance of being incarcerated. Academic underachievement is increased due to learning difficulties. Job instability, unemployment, relationship breakdown and substance abuse also feature in the known statistics. Depression and suicide rates are all much higher.

What is encouraging is that treatment can alter the course of these events in a high proportion of sufferers.

What is disturbing is that only about 20% of ADHD in New Zealand has been diagnosed and managed in any way at all. Imagine the public outrage that would be heard if only 20% of diabetics were being treated. Why is this so with ADHD? It is a combination of resistance and neglect.

In New Zealand and most developed countries ADHD is considered the province of paediatricians and psychiatrists. This can pose a number of problems. A paediatrician's role ends somewhere in the teens, just at a time in life when the issues around ADHD may be most critical. There is no training available to psychiatrists and no focus on ADHD. While ADHD may have a variety of secondary psychiatric consequences such as depression, anxiety, OCD and substance abuse it is primarily a neurological issue involving a relative lack of dopamine.

ADHD is a common, genetic problem which is life-long. It is relatively easy to treat so it logically, it belongs in general practice. The care of the health of the community has its roots in general practice where doctors have the ability to make at least a provisional diagnosis even if specialist help is sometimes needed. Ongoing care belongs in family medicine. There is a strong push at present in New Zealand to move as much medicine as possible from secondary to primary care, yet this has not happened with ADHD.

Much of the resistance to greater general practice involvement in diagnosing and managing ADHD has come from central government. GPs are not allowed to initiate medication for ADHD. Even when approval has been given for prescription of stimulants for ADHD, patients are required to go back to the specialist every two years to renew approval. In the public system this is a cumbersome process. Referrals to public mental health clinics in parts of this country are often declined due to a lack of resources. In private it is expensive and beyond the resources of many patients on only modest incomes.

Why are the barriers there?

Ritalin and Dexamphetamine can both be abused so the policy has been to attempt to control their availability. The abuse from a small minority has been used to punish the very needy

who number in the majority. Those with untreated ADHD are much more likely to abuse drugs than those on medication. Stimulants give non-ADHD people a buzz but in therapeutic doses ADHD patients only feel normal when, as they put it, 'the fog lifts'. The problem therefore emerges when ADHD patients pass their medication to others. Doctors and nurses working in the community are more likely than specialists to be aware if this is happening in their area. Strict control of prescriptions is much easier to manage in primary care. In New Zealand those who are into substance abuse have no trouble obtaining methamphetamine so tight restriction of medication for ADHD achieves very little.

While the evidence for the effectiveness of stimulant medication for ADHD is overwhelming, much more is needed than a prescription. Good management of ADHD begins with changing habits. Patients benefit greatly from learning to prioritise and perform one task properly before moving to the next one, from stopping to think before jumping into action or opening their mouths. They do much better without relying on substance use, such as alcohol, by far the biggest drug problem in New Zealand. Close friends or family who understand and encourage, without controlling or gossiping, make a major difference to someone with ADHD. Such people are hard to find.

With suitable supports in place, medication is usually very effective. Doctors and nurses need to be prepared to be coaches for ADHD patients. Voluntary support organisations such as the ADHD Association play a brilliant role in this way but could do much more with solid financial backing.

Changes could be made in the New Zealand health system which would substantially help this group of people. Yes, having money to spend on educating ourselves, teachers and the news media, and the public would help, but to revolutionise the care of ADHD, it requires a transformation in attitude among health professionals and managers and this requires leadership.

The results of diagnosing and treating ADHD can be incredibly rewarding.

Some patients share:

"These days I remember where I am supposed to be."

"It was like the fog suddenly lifted."

"No matter how hard I tried I was always late because I would forget where I put my keys, my wallet, my phone. Or I'd get busy with stuff that was more interesting and then just completely tune out."

"Someone would be talking about something real important like how their father had died and all I would hear was 'blah, blah, blah'. Then I'd just cut in and completely change the subject. Then I'd feel awful about it, but what can you do?"

But the other reaction is one of anger like this 40 year old whose ADHD was finally diagnosed:

"I feel like my life has been wasted!"

We have not done well and much unnecessary damage has resulted.

TONY HANNE

Dr J.A. Hanne (known as Tony) is a full-time GP with a special interest in ADHD. He trained at Guys Hospital in London before moving to New Zealand in 1964 where he has practiced ever since. For twenty years he was based in a group practice in Panmure before starting the current practice in Howick in 1987. Tony holds a Master's Degree in General Practice (thesis subject: ADHD in General Practice) and holds a Diploma in Obstetrics. He is a Distinguished Fellow of the Royal NZ College of GPs, an honorary lecturer in the Goodfellow Unit at the University of Auckland Medical School and has served as a medical examiner for the University. For nearly twenty five years Tony has held a special interest in ADHD, particularly as it affects adults. He was a member of the original government appointed National Guidelines Group on ADHD Policy and has written many articles on the subject of both childhood and adult ADHD.

PAUL G TAYLOR MBCHB MRCPUK FRCPC DCH

During my 34-year career as a specialist paediatrician, I have developed a strong interest in Autism Spectrum Disorder and enjoyed working directly with countless young people with autism, their families and their schools in Northland, Nelson, Wellington, the West Coast and Dunedin.

I have very fond memories of working in the mid and far North, based at Kawakawa Hospital, in the late 1990's, holding consultant paediatric clinics in the hot-spots of Northland: Kaikohe, Kaeo, Kaitaia, Kawakawa, Kerikeri and Rawene. I spent nearly a day and a half each week being paid to drive a health board Japanese import Toyota Corolla through some of the most beautiful rural and coastal scenery in New Zealand.

At the 2016 **Guide to Autism Workshops** held by the Children's Autism Foundation in Whangarei, Onerahi, Moerewa, Kaitaia, Kerikeri and Kaiwaka I heard a constant refrain that waiting for "assessment" and then "intervention" may take up to two and a half years. This contrasts with the 90's when the paediatrician-led service was capable of making a confident diagnosis, with the aid of standardized behavioural assessment forms filled out by the child's parents and school teacher, at the very first paediatric appointment, for which the waiting time was around six to eight weeks.

Since then we seem to have made autism much more complicated and difficult than it needs to be. Is this progress?

It is worth remembering that autism brings with it considerable strengths especially when these are recognised and nurtured. Attempts to restrict and "normalize" people with autism are usually much less helpful than approaches which celebrate autism and seek to unlock the amazing strengths that come with autism.

Autism is not rare or exotic. There are some 125,000 people living in New Zealand who have autism. About 75,000 of these people have never had their diagnosis recognised, often with unfortunate results. About 45,000 of these people attend pre-school and school. We have some 2,500 schools in New Zealand, staffed with some 105,000 professionals – a fantastic resource which remains uninformed and unused when it comes to autism.

It is those people who come into every-day contact with the person with autism who hold the key to success or failure. These are the people who need to change, not the person with autism. After all, the very essence of not having autism is the ability to create autism-friendly environments which support and nurture the person who has autism. Homes and schools abound with such people!

I am hopeful that continuing education about autism will leave people with a secure understanding that having autism is not bad news and that by helping young people become better at having autism we can all build on the unusual, novel and exciting potential that comes with autism.

PAUL G TAYLOR
Consultant Paediatrician (retired)

EDUCATION

Kids, teens and young adults with ADHD are faced with multiple challenges. If their diagnosis is known to teachers, other adults and peers you would think that would mean an increase in understanding and support. ADHD in particular continues to have an enduring negative reputation that makes every person given the diagnosis immediately evaluated around its authenticity. Do they really have a legitimate problem/difficulty or are they just naughty and the parents (or person themselves) using it as an 'excuse' for things entirely under their control. Currently, a significant number of teachers continue to fail to understand the core symptoms of under-control in ADHD and some (perhaps who have not had sufficient professional development on ADHD and its management) don't believe it is real and continue to blame children, teens and young adults for the difficulties, consequently providing little to no support.

A second hurdle is that lack of knowledge teachers and lecturers have about the effective management of ADHD in the classroom. This is changing as more newly trained teachers' start who are keen and trained to research methods of managing children with challenges.

New 'Digital Classrooms' and the additional use of digital devices has meant the attention of ADHDers can be more effectively engaged with game based math programs etc. It also has its pitfalls however, as ADHDers can get easily distracted by 'other' programs on a device.

RESEARCH

Research into the incidence of ADHD in NZ would be extremely helpful in establishing whether services are currently effectively reaching the population affected by ADHD. As it stands, we are in the dark, making estimates on access rates. This is especially true as NZ has a unique cultural demographic that may differ in its rates of neurodevelopmental disorders, and also appropriate interventions for each culture represented in New Zealand.

HEALTH

The awareness of the need for ADHD assessment is on the increase in New Zealand, and especially so for adults. The acceptance of ADHD as an authentic difficulty arising from neurological atypicalities is still a significant hurdle in the New Zealand culture. A lot of adults and parents are genuinely afraid of the potential negative consequences of an ADHD diagnosis for themselves or their children. They see the way friends and families react or negatively judge other people (or their children) with ADHD and fear that for their own. Nobody wants to become a social pariah. Families can consequently avoid this stigma and not seek assessment; and therefore therapy or accommodations that can make life more equitable for their child or themselves. Our greatest need as I see it, therefore, is in authenticating ADHD as the neurodevelopmental disorder it is. In the private sector, it is also important assessments for ADHD are irrefutably robust and comprehensive, so the public can be assured they are legitimate - thus over time hopefully increasing the belief the assessments are true and reflect a Neurodevelopmental Disorder just as legitimate as Autism.

Sadly, the social stigma also extends to the medicinal treatment options for ADHD. There are extremely effective medications that are quick acting, simple to trial at a low dose, and have been thoroughly researched to establish their safety. Yet these medications remain highly stigmatised, Ritalin especially, and so an option that may be extremely helpful is dismissed due to largely social concerns based on urban myths or old information.

In the public health system, ADHD in children is more effectively assessed than it was in the past, with many specialist teams and pathways now specifically dedicated to the assessment of Neurodevelopmental Disorders such as ADHD and Autistic Spectrum Disorder (ASD). At present however, the treatment options of ADHD with the District Health Board services are largely limited to medication only. Parents, teens and adults often benefit hugely from good quality information and support to understand and manage ADHD symptoms, which takes time and clinicians skilled in ADHD. There are still very few services for adults with ADHD and virtually none in the public system. The criteria for access to assessment in the adult public system is generally based on severity/detrimental effects on functioning and ADHD in adults can be less obvious and overtly debilitating as the presentation of a Major Depressive or Psychotic Episode for example. So adults are often not accepted for assessment with ADHD alone, as the entry criteria is largely not sufficient to include ADHD.

More people with ADHD also have a specific learning difficulty and as such, free Educational Psychology assessments (of learning) should routinely be completed. That way, challenges can be specifically understood and appropriate supports put in place. At present, the only way to get exam support through NZQA for example, is for families to pay close to \$1000 for an Educational Psychology assessment every two years.

In summary, individuals with ADHD and their families are often hugely affected by social stigma around the diagnosis and treatment options. This, alongside naivety from professionals and public regarding current neurodevelopmental understandings of ADHD, appears to further impede the provision and uptake of services from the public.

“It’s not the impairment that creates barriers for participation, it is people’s attitudes.”

-Kim

INVISIBLE DISABILITY: CUBE COLLECTIVE



*Special
Flowers*
Art by
Yaniv Janson

ADHD ASSOCIATION

The vision of the ADHD Association is for people affected by ADHD to live valued lives and realize their potential. The association was founded in 1977, by a group of concerned parents as a non-profit group, and remains focused on providing reliable information and support to those affected by ADHD across New Zealand. An estimated 2 - 5% of children have ADHD with both girls and boys affected in similar numbers. However, boys are more often hyperactive-impulsive and girls more inattentive.

A board of 8 - 10 members runs the association providing professional governance, alongside 2 paid employees. As awareness of ADHD has grown, and there are more adults and children being assessed, the need for good local information, referrals and support has also increased. To respond to this need, the ADHD Association collaborates with likeminded organizations to improve its effectiveness and allow greater reach into more diverse communities.

In particular, we work alongside Everyday with ADHD, VakaTatua, The Centre for Brain Research and the Invisible Disabilities Cube. We also link with ADHD groups around the country and professionals involved in assessment and treatment. There are currently around 800 paid members. We also provide information and peer support using social media via Facebook, with closed groups of around 2500 family and adult members.

The Association's mission is to educate, support and advocate for those affected by ADHD by assisting people in making informed choices, providing a repository of information that is accessible to all, being a centre of excellence for services offered, and being a credible national voice.

A multi-modal approach to management, tailored to suit the needs of each individual in both children and adults, has proven to achieve the best results. Understanding and accepting ADHD is so vital for those having to deal with it on a regular basis. Teachers, siblings and parents need to know they can have a positive impact by showing appreciation and acknowledging a person's ADHD. The ADHD Association provides links and information to help affected families with management strategies and counselling as well as coordinating workshops and programs with Everyday with ADHD NZ.

Don McGlashan, the patron of ADHD Association is quoted "The endless variety of the natural world is reflected in us as well. We aspire to conformity, because it makes us easier to govern, to educate and to sell things to, but really we should be celebrating the fact that no two people are made the same. We need to cherish difference. Some of the most non-conformist people are exactly the ones who might help humanity make those quantum leaps that it makes from time to time - in science, the performing arts, philosophy, and literature. If we can learn to be flexible in our assumptions about people, we can begin to view difference not as a difficulty, but as a gift." (ADHD website)

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Autism New Zealand comprises parents/caregivers, schools, professionals working in or having an interest in the field of autism spectrum disorders and other service workers. It originated as a subcommittee of IHC and became an Incorporated Society in 1995.

Autism New Zealand Inc. provides support, training, advocacy, resources and information on autism Spectrum disorders including Asperger's Syndrome. We are a national organization with 16 branches throughout New Zealand. Each branch is run by professionals and supported by volunteers. They each provide various levels of support. Outreach coordinators work part time due to limitations in funding.

Our vision is "Empowering people living with autism". The main purpose of Autism NZ is to provide support, resources and information on Autism Spectrum Disorders to those with these conditions, their families/whanau, caregivers and professionals. As part of this service, there is a telephone support and information line 0800 Autism available Monday - Friday, educational programs and seminars for parents and professionals, as well as advocacy for those who need someone who understand Autism Spectrum disorders, to help when communicating their needs to other people. Other activities and services can include, music therapy, social skills programs, holiday programs, coffee mornings and regular meetings for parents and interested people with guest speakers.

Children and adults who have an Autism spectrum disorder look the same as other people, and due to the invisible nature of their disability, it can be much harder to create awareness and understanding with communities. These disabilities still remain relatively unrecognized or unknown among the general population, yet it affects 1 in 66 people (approx 65,000 New Zealanders)!

An Autism Spectrum Disorder is a life-long developmental disability that affects social and communication skills. People with this disability can also have accompanying learning disabilities. Everyone with the condition shares a difficulty in making sense of their world.

Autism NZ offers information through its website www.autismnz.org.nz. Pamphlets, parental guides and information about Autism are all free for downloading. Put together these resources aim to provide an in depth information pack for parents, caregivers, educationalists and professionals.

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Autism Spectrum Disorder (ASD) is believed to occur in 2.64% percent of people.

The Children's Autism Foundation (CAF) is a not for profit organisation committed to meeting the growing demand from families and the community for quality support services extending from Auckland to and throughout Northland. CAF supports families with young people from 1 to 21 years of age. Over 2,500 families, community members & professionals are on the CAF database and receive regular communications & services.

Over the last 15 years the organisation has expanded to offer extensive services that meet the needs of families, carers and professional people. We offer one to one family consultation, professional development within the workplace, physical development programmes, and positive parenting programs. Children learn and develop skills through attending play courses, and we offer friendship and social skills groups which includes offering workshops on understanding autism. Skill levels range from emergent diagnosis through the stages of child development so individuals learn strategies for behaviour, dealing with anxiety, social and friendship skills and sensory issues in relation to autism. Children's Autism Foundation also works tirelessly to raise public awareness about autism.

The Children's Autism Foundation provides qualified staff and contractors to facilitate supportive services in homes and venues across Auckland and Northland. We equip families and communities with the knowledge, coping skills, strategies and the confidence to effectively support children with autism in the family environment and the wider community.

In recognition of both the financial costs and logistical complexities associated with raising a child affected by autism CAF remains committed to ensuring that services are affordable and accessible. We believe in going directly to the families to offer our assistance. Families often experience financial hardship and emotional distress, so this is one way we can help these families. Our services are not government funded; however, they are very important for supporting a family and an autistic child's development.

In the last year the Children's Autism Foundation has provided the following autism services for families:

- 1458 direct services to families in need through their Outreach program
- 32 Positive Parenting - Stepping Stones visits to families
- 123 families (children and parents) attended weekly social skills training programs
- 221 families (children and parents) attended weekly physical activity programs
- 802 family members attended workshops

A total number of 3886 services were provided by Children's Autism from April 2016 - March 2017, 2636 family services and 1250 people in the ASD workforce training programs.

The Children's Autism Foundation's family-centred programmes are unique. They can complement services provided by other agencies. CAF have a proven track record of providing a quality service to families/whānau of children with autism, providing advice, support, holistic and family-centred solutions to help families manage the intense emotional and practical impact of autism.

National and international studies have shown that:

- ▶ The cost of raising a child with a disability can be up to three times that of raising non-disabled children.
- ▶ Children with autism are three times more likely to be bullied
- ▶ There is a correlation between autism and physical and sexual abuse
- ▶ There is a high percentage of people with autism and ADHD in prisons
- ▶ Autism should always be considered when dealing with suicide attempts
- ▶ Providing parent and child assistance in joint social skills programmes helps families
- ▶ Approximately 70% autistic adolescents suffer with mental issues (e.g. anxiety, depression)
- ▶ Autism can cause social, friendship and family challenges which can lead to isolation.

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DISABILITY CONNECT

Our organisation has been serving the Auckland community for 22yrs. We have a small staff of five full time equivalent members based in Penrose is open five days per week. The Parent and Family Resource Centre Inc. trading as Disability Connect is a Disability Information Advisory Service operating throughout Auckland, north to Warkworth and south to Pukekohe.

As an Incorporated Society we now represent over 5200 members. This better describes what we do as an organisation. We connect individuals with a disability, their families and professionals with information and support. This is the main reason Disability Connect participates in the Neurodisabilities Cube. Connections and working alongside other providers allows us to better support families and be part of a group that is proactive in promoting positive change.

As an incorporated Society we represent our members who now number over 4000. Our organisational aim is represented by our Vision, Mission and Core Values. We believe that disabled people and their families are able to lead the lives they deserve. We empower disabled people and their families through leading social change, we respect and support their right to 'choice'.

As an organisation which is not specific to any one particular disability, Disability Connect is well positioned to address a huge range of issues including but not limited to; Ministry of Health funded supports, Needs Assessment and Service Coordination (NASC) role, Ministry of Education supports, Work and Income supports, unpaid supports in the community, Transition out of school to community, disability sector 'navigational' support regarding how the various agencies and support options operate, etc.

We assist families through the delivery of disability information and advice. We use phone and email communications directly with individuals with a disability and/or their family – answering a broad range of questions regarding disability. Face to face consultations are held directly with individuals/families to address questions and provide support. We offer seminars on disability topics including Transition from School to Community, Individualised Funding, Work and Income Supports, Living Options for a Person with a Disability, Education Legal Issues and Planning for Adulthood (legal rights framework for a person with a disability). Disability Connect produces several publications free to the community including:

- ▶ Disability Support Guide – broad generic guide to the New Zealand disability sector including policy/legislative environment, government funded supports, on-Government supports, etc. – available in English, Chinese, Korean and Arabic
- ▶ Networker magazine – produced six monthly on a topical issue
- ▶ Four Go Flattening – an informational resource on how to use Individualised Funding for a family governed flattening arrangement for a person/s with a disability

In 2014 Disability Connect began a Culturally and Linguistically Diverse Disability Information Advisory Service via a contract with Counties Manukau District Health Board. This service targets the following ethnically diverse communities of south Auckland: Chinese, Indian, south Asian, Middle Eastern, African and Hispanic families raising a child with a disability. Under this service we run the very successful Chinese Families Support Group and Indian Families Support Group. This is a free service for families.

In February 2016 Disability Connect began a Social Work service aimed at addressing the sometimes more complex, multi-faceted needs some families have when raising a child with a disability. For some families there exists a spiralling cycle of unaddressed needs, unidentified or inaccessible supports and several agencies involved. Our Social Worker takes a holistic and broad view of each situation and helps families identify a positive pathway forward. This is a free service for which families can self-refer (or referral via a professional).

Contact:

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Renaissance Group was born in 2001 in the Papatoetoe garage and has grown substantially over the last 15 years to become one of the most successful providers to Supported Living Services to disabled people in New Zealand. From modest beginnings, Renaissance employees now support over 200 people to work towards and live their dreams, just as others do every day. These people are able to look forward to growing up and being ready to leave home, go flatting, socialise with friends and extended whanau, form long lasting relationships and/or romance with someone they love. This is what Renaissance considers to be 'normal practice'. Renaissance staff helps and supports their clients to imagine and design their futures. This is achieved by offering them choices and options. The goal is to enable people with disabilities to live as independently as possible by treating them fairly, with respect and dignity.

Renaissance doesn't only use one model for their service delivery. They work with the principles and application of "Social Role Valorisation" (SRV) which is a set of ideals that help address exclusion, marginalization and stigmatising of all people our communities.

Establishing a mixture of both formal and informal relationships throughout services, ensure relevant relationships and subsequent outcomes are for the benefit of people who want to not only do ordinary things in ordinary spaces, but also work towards doing some fun and exciting stuff in some amazing places! The Renaissance vision of supporting clients goes beyond the provision of basic care and aims to continually bolster each person's ability to reach their potential and continually work towards living an independent life. Each person, is given the opportunity to create their own support plan based not only on their needs, but their personal goals. Learning how to cook, find employment, learn about personal finance, or learning skills required to look after themselves in their own home are all options available to them. Plus the more future focused goals around personal fitness, joining a gym, joining a tramping or hiking club, learning to play sports and joining a local club are actively pursued and encouraged as long term progressive initiatives.

In the early years, Renaissance recognised there was little support for ongoing training on a less formalized basis to help build practical skills. Day to day skills around communication, coping strategies, behavior changes and many of the other challenges that face support people every day were not an ongoing option for people who did not fit within mainstream education 'ideals'.

As part of the journey, and also as a result of Renaissance successes, Portal was developed to assist in the area of training and development. Training and personal development around specific areas of need around supported living is difficult to personalize, so workshops around understanding disability needs from a humanistic perspective were needed. At the Renaissance Group conference in 2014, Portal was born from a concourse of workshops that highlighted a need for further understanding and ongoing development for everyone in the disability sector, as well as those who live on the precipice of self developing knowledge. Together Portal and Renaissance positively influence everyone from the public, volunteer groups, employers, parents, educators and medical employees by providing innovative training through dynamic facilitators. The experienced people who deliver a wide range of workshops and programs are not afraid to challenge stagnant processes, or question policy as opposed to practice within any sector, where it has a direct relationship with or is responsible to disabled people. This methodology gives results that really matter and that can immediately input into any organizations day to day practice while still retaining organizational integrity and values. Portal prides itself for delivering workshops that help participants learn to develop strategies that

work, using people that know and already use or live an inclusive focused life, offers a powerful toolbox of skills.

Renaissance uses its many resources and links to reach out to any location in New Zealand. Disability and exclusive practices are not just an issue for cities and large towns. Many smaller areas around New Zealand are disadvantaged not only by distance, but in a lack of local services in all areas when trying to develop their community's strengths and get what they need for assistance. Simply by being accessible to these small areas ensures those who want choices in their support options can have the same level of access of those who live in larger centers. The relationship that's been established with the Invisible Disability Cube came as a result of a program being run for parents of young children who have a disability. Parents who struggled to access services their children needed to help them through diagnosis, ongoing support needs, providers, education and social needs. At the conclusion of this series of workshops, it was through inviting other organisations and providers into this learning space that enabled these families to find answers. By sharing access to the learning space and using our 'community inclusive practice', a group of knowledgeable people, - parents learned about alternative services and how to access and build relationships that are still helping to support that community today - through the original families. Renaissance believes that it takes a community to care for a disabled child, and their family; and is constantly looking at where we can assist and influence positive decision making by everyone concerned.

Building mutually beneficial relationships with other providers is one way that Renaissance ensures disabled people are offered and delivered the best service possible. Working with other organizations means that disabled people can work with more than one service provider if that's what they choose to do. The SRV method is person centered using resources that are available to ensure that each person receives the practical support they need to live a good life. This gives growth and choice back to smaller communities helps strengthen their own skill base for future development. It also influences the whole community to reflect on the way they view the people who have diverse needs. To reiterate and provide context around what Renaissance and Portal provide, director, Barry de Geest travels New Zealand talking to schools, service groups, community collectives, conferences and forums about self empowerment and the possibilities that exist for everyone.

Renaissance is always looking at new methods of supporting clients, family and whanau, the public including people in positions of power, with the intention of creating and consistency in the delivery of services to everyone in all communities across all its diverse and wonderful population.

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PHAB



PHAB Association is a sector leading youth disability organisation with over 40 years' experience delivering outstanding social and recreational activities.

The aim of PHAB is to see all people included and accepted, and participating meaningfully in their local communities.

PHAB is a social network that fosters a sense of independence, autonomy and confidence in our talented members.

PHAB currently run 22 weekly social groups across Auckland from Orewa to Henderson to Papatoetoe with two clubs running in Christchurch. PHAB have a fully accessible Youth Space in Takapuna that is enjoyed by over 120 people with and without disabilities each week. PHAB Pasifika is a branch of PHAB located in Papatoetoe based on culturally appropriate methods of engaging Pasifika youth with disabilities, their families and their wider networks. PHAB Pasifika has a performance art based group called Phusion that seeks to empower members to demonstrate their unique talents through dance and performance and to have a way of meaningfully contributing to their communities. In addition to social clubs PHAB run discos, Fun Days Out, a bi-annual ball, ACE a health and nutrition class, PHDs a fun holiday based program and PEERS a 3 day per week lifestyle course.

PHAB hold our members at the centre of all we do, with youth designing their own programs for themselves, sitting on every level of the organisation as members, volunteers, paid staff, youth representatives and even sitting on the PHAB board. PHAB members, staff and youth representatives frequently consult with other organisations to provide feedback from young people directly or to help co-design and co-develop services and programs alongside our members.

PHAB are passionate about working together to ensure all people have a voice and are heard, and to support the changes that need to occur in order for our remarkable members to have true inclusion, community participation and the confidence and autonomy to build for themselves meaningful and satisfying lives.

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REPORT REFERENCES

WORKS CITED

McKenzie, N., & Garland, J. (2015).
Information Gathering for Autism Workforce across New Zealand 2015.
Auckland: Te Pou o Te Whakaaro Nui.

Starr, K., & Janaj, N. (2016).
Challenging the Barriers: Ensuring access to Education for Children with Special Needs Education.
Auckland: YouthLaw Aotearoa.

Government Response to the Report of the Education and Science Select Committee, on its Inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia and autism spectrum disorders in primary and secondary schools.

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Yaniv's work can be found here:

<http://www.yanivjanson.com/>
<https://www.hrc.co.nz/yaniv-janson>
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