

Perceptions Control Reality

Our family's journey to embracing an inclusionary vision

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I read some time ago that the new brain science suggests that our perceptions, in a sense, create our reality. The same author suggests that another of the realities of human development is the need to be “included”.⁸ “Being included” is what creates “belonging” and, as a parent, I have come to understand the importance of “belonging” particularly for children; beyond the basic necessities of life, I consider it to be at the top of the hierarchy of human need. For children with disability, that need is perhaps even greater.

However, I have not always seen things that way and in the five years since my son Julius was born I have begun to appreciate the impact of our cultural and historical perceptions of disability and how they shape the realities of those who experience disability. In particular, I have come to realise that our previous generations' cultural upbringing did not acknowledge “belonging” as a universal human need and did not recognise “being included” as a universal human right⁹. It has been through this reflection that I have come to understand why and how our contemporary cultural perceptions of disability became so distorted.

When Julius was born, we welcomed him into the world as the precious child that he is. But when the words “Down syndrome” were first spoken the next day, it seemed to us as if everything had changed; I felt as if I was no longer holding the same child. There were many emotions, fear and confusion. We didn't know what future we could hope for Julius and what path he would follow but we *assumed* it wasn't going to be the same path as his older sister, Laura. What I have come to know as historically-biased perceptions flooded my responses. As I cradled my days-old child, I turned to one of the maternity ward nurses and asked, “Do you know which are the best 'special schools' around?”

⁸ Wills, D. (2010) *Our brains are hardwired to be inclusive*. (www.pledg.com/what/)

⁹ Article 3 of the *United Nations Convention on the Right of Persons With Disabilities*, to which Australia is a signatory, calls for “full and effective participation and inclusion in society” and article 19 calls for recognition of the “equal right of all persons with disabilities to (...) full inclusion and participation in the community”. Notably, article 24 sets out rights in relation to education and requires State parties to ensure “an inclusive education system at all levels” directed to “full development of human potential” and that people with disability are “not excluded from the general education system on the basis of disability”.

Through the lens of our culture we perceived that Julius was “special” and so we expected that his life would be spent in “special” places and subject to “special” rules. In this sense, “special” was a word that served to exceptionalise and separate him and that did not feel special at all. We, Julius’ parents, like previous generations, grew up through a time when people with disability were kept away from others and mainstream society, defined by institutional segregation of one form or another. Those assumptions and that “reality” were so deeply entrenched that it did not occur to us to question their basis or validity.

“Inclusion”? We had never heard the term and when we finally did, we were skeptical at first because it was an idea that seemed to go against everything that we, as non-disabled people, *thought* we knew about people with disability and what *they* needed. Until then, we had not had the opportunity to imagine any better; we did not grow up with children with disability, in the family or at school, and we had not worked in a workplace with adults with disability.

Our perceptions of Julius and his path were ultimately determined by a set of cultural assumptions or beliefs that shaped our expectations about our son and his condition, including aspects of it such as intellectual impairment. We did not consciously reflect upon or articulate those assumptions or beliefs in any way but they were the ready-made prism through which we viewed Julius and which informed the range of questions we asked and how we asked them.

One crucial assumption that we made was that people should be “normal” and that falling within a “normal” range is more right or legitimate than not. When you think about disability and functional impairment, if you accept the categorisation of people into “normal” and “abnormal”, then you are necessarily seeing a person with a disability from a “deficit” perspective, as being “less than” and therefore not fully belonging. After all, these are the questions that are asked of us as parents, as soon as our children come into contact with the “human services” professions; “What is his IQ? What *can’t* he do? How ‘severe’ is he?” Things that determine the types of services and how much funding Julius will get, also define him by “how abnormal?”

In some way, it would have been easy to accept that perception of Julius and to start shaping his reality from that position. Fortunately for all of us, we also came into contact with others in our early journey who dared to reject that perception and to replace it with an alternative vision based on the recognition that human variability, including the experience of disability, is as universal a reality as the fundamental need for each and every member of our human family to be included and to belong. And this inclusionary vision sounded so much closer to what we had in mind for all of our children than the separate “special” world that was being offered to Julius. So we embarked on a road less travelled by families like ours, although in some ways it is also the road more familiar, because it is the same road we had always hoped to travel as a family although somewhat bumpier than we envisaged.

We have faced some challenges in the early stages of Julius' life but have also held firm to the view that we would prepare him for mainstream school like his sisters and his peers. In his case, that has meant some surgery for his hearing, getting used to glasses and other assistance of this nature, but it has been primarily reading to him, teaching him numbers, letters and colours, encouraging him to talk nicely to others and involving him in social activities in the community like gymnastics and dancing that have made the biggest difference. We also avoided much of "early intervention" – especially that based on "special needs" – when we knew his were fundamentally typical "boy" needs.

What we have come to realise in taking this journey, as time has passed and as Julius has grown up in our family, loved and valued by his parents, his sisters and his extended family, is that it is imperative to change the way that we, the community, think about disability – to see the individual, unobscured by assumed limited expectations as to potential and free from the stigmatisation that is inherent in defining people by medical labels.

I believe that students with disability and their parents actually need to (and therefore should) feel that they "*belong*" in the mainstream school environment, i.e. that they are welcomed and supported – not merely accepted or tolerated. The school environment is not only the place where individual students' self-perceptions emerge but also where the next generation's perceptions and values are culturally shaped.

Further, the evidence is that a genuinely inclusive cultural environment is critical to successful inclusion and the maximisation of academic, social and health outcomes of inclusive measures. An inclusive culture and perspective is the oxygen necessary for inclusive measures and all students (particularly students with disability) to thrive.

As we enter the more formal aspects of Julius' education, we hope to work with a structure that adopts a cultural perspective that is welcoming, not only of Julius and our family, but of all students. Essential to that hope is the mainstream schooling community being able to appreciate the importance of developing a genuinely inclusive cultural response for all students. This necessarily requires being able to identify, not only the overt but also the more subtle indicators of exclusion, as well as recognising our entrenched history of exclusion and the subliminal constraints of a cultural response that is based upon that history. The following table has been developed as a succinct guide to facilitate school administrators, teachers and in particular parents to reflect upon and strive towards developing that necessary appreciation of perspective.

| Historic Cultural Response to a Student with a Disability | Historic Cultural Response to a Non-Disabled Student | What an Inclusive Cultural Response should be for all Students |
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| Burden | Benefit | Every student is welcomed and belongs – all students have the potential to learn, contribute and enhance each other’s academic and social development. |
| Abnormal | Normal | Human diversity is normal and we all belong. Disability is part of human diversity. |
| Helping is charity/ extra/gratuitous | Helping is expected/ an entitlement | All students are entitled to be assisted as of right - each student is an individual and their individual needs should be addressed. |
| Child has 'special needs'/'additional needs' | Child has human or normal needs | All needs are human or normal, but the way needs are met should be individualised/cater for functional impact of disability. |
| Child is an 'add on' | Child is automatically included | Presence and full participation are rights and expectations of all students. |
| Always pressure to separate child and deal with them specifically | Always mixed with others | Students learn best together - the best learning occurs in cooperation so all students are sometimes helping and sometimes being helped. |
| Grouped by least desirable/ stigmatising characteristic (i.e. disability) | Grouped by age | Students should be grouped by age - particularly important for students in danger of being seen as developmentally “younger” than they are. |
| Inclusion is conditional | Inclusion is automatic | Inclusion is not an issue – avoiding exclusion (including subtle exclusion through “soft prejudice”) is the key consideration. |
| Focus is on ‘can’t do’ | Focus is on ‘can do’. | Expectations are key to success - expectations should be high for all students and each student supported to meet expectations. Shared belief that nothing exceptional is achieved without high expectations. |
| Lack of learning is due to diagnosis/ disability | Lack of learning is a problem for the teacher to address | Teachers rely on evidence-based approaches to maximise the learning for all students – conscious of need to avoid stereotyping, reduced expectations and stigma of “medical labels”. |
| Misbehaviour is due to diagnosis/ disability and outside of teacher capability. Do not apply normal sanctions. | Misbehaviour is a problem to be addressed by teacher and school using normal sanctions. | Normal sanctions apply to all students but may sometimes be carefully adapted to life experience and need for more structured responses in individual cases - teachers are sensitive to importance of belonging and positive feedback and impact of a lifetime of exclusion, stigmatisation and rejection. |

| Historic Cultural Response to a Student with a Disability | Historic Cultural Response to a Non-Disabled Student | What an Inclusive Cultural Response should be for all Students |
|--|---|--|
| Student has limited potential determined by IQ and diagnosis/ disability - outcome not determined by quality of teaching or motivation of student. | Student has unlimited potential - outcome determined by quality of teaching and motivation of student. | Teachers are sensitive to the history of low expectations and “learned helplessness” of individual students - teachers work with parents to increase expectations and maximise student learning. |
| Unable to go on camps, trips etc. without parent/ dedicated adult assistance. | Automatically included on camps without need for specific assistance. | Peer support and regular support structures are used to support all students in novel situations - teachers consult parents about individual students and organise any normative safeguards accordingly. |
| Inclusion dependent on additional resources. | Current resources shared with all students according to need. | All students share the school resources according to need - emphasis is on supporting each other through collaboration and peer support rather than by automatically requiring teacher aide support. Teacher aides are used as supports to the teacher and assist all students to develop greater independence and better social relationships. |
| The problem is a medical one. Doctors and therapists are the key advisors. | Teachers and parents are the experts on the child. | Teachers and parents are the key decision makers with advice from others utilised when appropriate, sensitive to risks of “medical labels”. |
| Can be included as long as ‘the gap’ is not too large. Then they have to be segregated. | If the student is not keeping up they are supported to achieve as much as possible. | Students are involved in all regular lessons with emphasis on the core concepts being attained by all students - multi-level teaching employed as well as universal design concepts in lesson planning. Fundamental assumption is that ‘keeping up’ is not a requirement to be a class member - all students are there to learn as much as they can as well as to learn how to be a part of society. |
| The child needs to be taught in special ways by specially trained teachers who know about the diagnosis. | Lessons use evidence-based approaches to achieve positive outcomes. Adjustments are made to cater for individual learning styles. | Good teaching works with all students. Focus on using evidence-based strategies, parent partnerships and collaboration with colleagues. |

| Parents of Student with Disability | Parents of Non-Disabled Student | What an Inclusive Cultural Response should be for Parents |
|---|--|--|
| Teacher fears disappointing "unrealistic" expectations of parent. | Teacher anticipates meeting expectations of parent. | Teachers are sensitive to the life experience of families and the critical importance of building partnerships. Parents are seen as the expert on the individual student and a key partner in ensuring the maximum benefit from the school experience. |
| Teacher communications complicated by "managing" expectations of parent and lesser capacity to identify with position of parent. | Teacher communicates with parent with confidence and as person that they can relate to. | Teachers approach parents as partners in the educational process, and the senior partner in determining life decisions for the child. While the teacher is the senior partner in the classroom, classroom decisions are based on input from the parents as well as colleagues. |
| Parents who want full inclusion have not accepted the reality of their child's disability. Counselling may be required. | Parents have a range of expectations and beliefs about their children, all of which are valid. | Schools accept that in order to include all students, the school culture, processes and interactions with families need to be inclusive and collaborative - parents are a key component of successful systemic change. |
| Inclusion of a child with a diagnosis/ disability requires team decisions involving a full range of therapy and educational staff with a parent present to understand the decisions made. | Teachers communicate with parents informally or in structured parent-teacher meetings. Any external involvement is by agreed invitation. | Decisions are made by parents and teachers in partnership, informally or where necessary using structured parent-teacher meetings. External involvement by agreed invitation. |
| Parents are concerned that siblings of their child with a disability are at risk of secondary exclusion by student peers, with associated social and health risks. | Parents have no real concern of social exclusion of their children by their student peers. | Schools and teachers should take a "whole of family" approach and be sensitive to secondary exclusion issues that may affect siblings of students with disability. |

* **Note:** For further reading, see generally Dr K Colgan, *Inclusion in Education - Issues Paper* (2013), Jackson & Wills, *The 2013 inclusion report card* (2014) and Siblings Australia website (www.siblingsaustralia.org.au)