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**Special
Inclusive Education
Issue**

The Australian Institute on Intellectual Disability

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Contributions (email attachment if possible to aiid@ncid.org.au) and correspondence to:

Australian Institute on Intellectual Disability
PO Box 771 Mawson ACT 2607
Tel/Fax: (02) 6296 4400

Internet Email: aiid@ncid.org.au **Home Page:** <http://www.ncid.org.au/aiid.htm>

Editorial Committee: Norma Rigby, Dulcie Stone, Monica Gourley and Mark Pattison

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i Editorial

Building Inclusive Capacity - One Community at a Time The National Significance of the Demonstration of Inclusion in Esperance, Western Australia

In the following articles, we explore a community in the throes of change. Readers will be introduced to people learning and working together to build the inclusive capacity of one community for this and subsequent generations of children who grow up there. What is discovered is that teachers and parents can understand one another and, when they do, the children of the community and their schools benefit.

In commissioning this issue of *Interaction*, AIID wanted to see if the international shift towards inclusive education for children with labels of intellectual impairment would transfer to the coalface. Answers were sought to a number of questions: Was inclusion just some nice sounding rhetoric (as the critics suggest), or was there an actual application of *science* to inclusion that Wills and Jackson¹ described to us over a decade ago? What were the salient features that would move one State in a certain direction while others were moving in another; if the form of advocacy a group of parents took, mattered? Did the history, the domination of the medical model or labelling practices have any influence?

Many of these answers were found in the example of Esperance, in the exemplar of WA's educational leadership and in the demonstrative advocacy of the PLEDG association of parents.

The contents of these articles share several common themes – topics that *Interaction* has explored in some depth from about the mid-90's, when a special edition on inclusive education was first published. In 2001², a parent sight-line report card was prepared on the health of our education systems for the United Nations – it was discovered that most States were then performing, in their eyes, “well below grade level” on matters of partnership with parents and actual welcoming of children into local schools. (Only Victoria and Tasmania scored above a D level just 7 years ago.) In hosting the 2002 *Inclusion International* conference, AIID hoped to measure Australia with international exemplars. Only a few of our national examples stood up to the international benchmarks.

Through our parent affiliates, AIID heard that WA had taken a novel shift towards creating the choice for inclusion, at least in part through the leadership of WA's then Minister of Education (now Premier), Alan Carpenter.³

Stories from teachers and parents were recorded in two further special editions on inclusive education. Among them was the story of Julius, which became a practical exemplar of multi-level teaching design.⁴ In this issue of *Interaction*, it is shown how this shift is growing in partnerships where parents are valued as senior partners in their children's development, where their decisions for inclusion are told and heard by educators and solutions are built from the local level upward.

⁴ Australian Institute on Intellectual Disability

Parents in True Partnership

Until you experience the delivery and acceptance of the stories told in this issue of *Interaction*, it is hard to imagine the feeling of a parent telling their personal story to a group of teachers and being “heard” deeply about their choice to follow an inclusive pathway and then having the choice respected and honoured.

When you then see parent-teacher-community forums *brainstorming* how to solve an inclusion problem together, you know you are seeing something *substantial*.

In most every jurisdiction around the country, parents and teachers have been met separately. Mostly the dialogue is steeped in pain and anger and the advocacy is political, legal and confrontational. Not here. Not in the example of Esperance. The history of such is evident in the cautious first workshops. However, after a few experiences, they have quickly moved to partnership. *Should we include* is not up for discussion. How to make it better for this or that child, teacher or whole school absorbs the full time.

Leadership . . . of the political kind

A critical element of successful inclusion in education, as set out in the research, is that of leadership⁵. Listening to a great many parents around the country, what makes WA stand out above other jurisdictions is its leadership in moving towards a paradigm of inclusion in the face of a historical habit of segregation.

There are several critical leadership elements discussed by Dr Jackson in his article, *Helping Systems Change*.

Alan Carpenter’s political leadership (formerly as the WA Education Minister and now Premier) was paramount in securing for parents a genuine choice to pursue an educational pathway of inclusion in a regular class at a regular school, alongside their child’s peers. In 2003, Mr. Carpenter wrote to AIID setting out the State’s vision:

Building the capacity of schools to manage diversity more effectively is a key outcome of this Government. Increasingly, schools are being tested in terms of how they reconcile the need to manage diversity while at the same time strive to eliminate discrimination. In acknowledgement of the increasingly diverse student populations in our schools, I have commissioned a comprehensive review of educational services for students with disabilities in Western Australian government schools. I anticipate that the Report on the Review will present a strong foundation upon which the Government and the Department of Education and Training will build safe, inclusive and engaging learning environments for all students. This work acknowledges the importance of shared global values and the need to effectively harmonise the growing diversity of students within our schools.

In line with the values articulated in your paper⁶, the Review strongly supports a move away from a traditional medical model of disability and the negative connotations associated with the term ‘special needs’ towards the adoption of a social model in which the educational needs of students are paramount. In line with national and international trends, the social constructs of disability education have been promoted. To this end, the term ‘students requiring teaching and learning adjustments’ has been adopted to facilitate the need to making appropriate adjustments to the teaching and learning environment.

While many Australian States may have similar rhetoric, Alan Carpenter showed a strong

understanding of the history and power of the medical model and labeling, as well as turning the spotlight OFF “fixing the child” and onto “making adjustments to include”. This was a bold step and, through his actions, provided a choice for parents to pursue inclusion without undermining the parents’ decision – something not seen in other jurisdictions. Such political leadership opens up the opportunity for schools, principals, teachers and parents to figure out *how to* achieve inclusion without fear or compromise.

As a result, exemplars of inclusion throughout WA are being seen. Esperance is such a case in point and hence AIID is keen to share this with other parents and professionals throughout Australia and the international community.

The political leadership is supported by a structure of supports for schools. Anjie Brook and John Heska, two senior educators in the WA Education Department provide a practical example of WA’s commitment to building the capacity of school communities to include the diversity of its community members in Government schools. Without wanting to critique the range of practical responses to WA’s inclusive education policy, the early development of a professional culture is being seen that is seeking to build its ability on how to include children previously excluded from regular classrooms. Unlike anywhere else known of, this training culture is including parents as significant partners in teaching and developing these processes, and is growing their capacities together without thinking that anyone has all of the answers.

In the case of Esperance, a cooperation and collaboration has been witnessed between the WA Education Department and PLEDG (a parent association) in seeking to bring knowledge and resources to a regional community - including the definition, research and practical application of such on specific issues of inclusion such as reading, developing (rather than managing) social behaviour and practical problem solving.

This is a collaborative approach that is desirable, for it places parents in legitimate leadership roles – in partnership with representatives of the WA Government who are charged with building the Education Department’s capacity to include their children.

It is realised that WA’s commitment to making every school in the State inclusive is just 5 years along the track, yet it is setting off in a direction that few whole communities have traversed. It is important that we capture that which is promising and also be prepared to let go of that which is not. The experience of inclusion in Esperance offers something promising.

Leadership . . . of the parent kind

In this issue, Wills introduces a term which will be new to many – *demonstrative advocacy*. At the heart of *demonstrative advocacy* is the decision by parents to rigorously pursue and demonstrate an inclusive education and life pathway for their children. It is more than a legal or political rejection of segregation as being unsound. It is demonstrating, through how one lives one’s life, what inclusion looks like.

It seems so simple to say it now; yet inclusion is a significant decision, which sets a different course for child, family, school and community. Demonstrative advocacy suggests a greater degree of strategic work rather than mostly political and lobbying work. Wills’ 90:10 rule suggests we work to show development and inclusion 90% of the time, and work the other 10% to change systems through conventional advocacy. Making such a decision can be a struggle – a time of being torn. As parents and organizations, we are skilled in verbal advocacy. We are

not so skilled in demonstrating what we want. As a parent recently told us – “choosing inclusion and doing it rigorously was like *recovering from the comfort zone*”.

The parent leadership required to pursue inclusive education is therefore considerable. In Esperance, parent leaders have decided to set about walking an inclusive education pathway through their own personal demonstrations. As an association, they have set about engaging with the local community, the Department of Education and Training, and teachers to join them in building a new pathway.

This is a new habit – a good habit - something which is nationally significant.

Endnotes

¹ Darrell Wills and Robert Jackson. (1996). Inclusion: Much More Than “Being There”. *Interaction*, 10#2, 19-24.

² *Interaction*, 14#2 & 3

³ The West Australian, Monday April 2, 2001. “Education Minister Alan Carpenter has announced the biggest review in two decades of educational services for the 8,500 disabled students attending government schools in WA.”

⁴ Darrell Wills. (2004). Escaping the Continuum. *Interaction*, 17#2, 21-23

⁵ Darrell Wills and Paul Cain. (2003). Teacher Education For Inclusion. *Interaction*, 16#4, 23-31

⁶ The Minister was responding to the Wills & Cain article, *A World Without ‘Special Needs’ – The Naked Truth*. *Interaction*, 16#4, 32-34

Apologies!

Due to production problems, there was a delay in completing this issue of *Interaction*. We apologise for its lateness and any inconvenience caused.

Demonstrative Advocacy: The Example of Esperance

by Darrell Wills

Director

Parent Learning Education Development Group (PLEDG)

The struggle for inclusion in today's society can possibly be understood best as a multi-millennial quest to recover from a long engrained habit of segregation. Over many generations, we have been taught by our elders to believe that some people are not welcome for who or what they are. Our generation suffers most in these regards from echoes of the teachings of eugenics in the late 1800's and early 1900's. A moral verdict then held impaired people responsible for the ills of society¹ - and in this time a "new science of eugenics was invented" to support their moral decision. It was passed down to us. We entered a world where segregation was commonplace. To move to inclusion we must rethink the position of eugenics in our future society. A moral examination and decision are required.

In the euphoria of the 70's, many of us thought that the science of development, the science of integration and, later, the sciences of inclusion would surely be enough to sweep clean eugenic thought and its major tool, *segregation*, from our schools. Yet for 40 years we have not done so. We have had no evidence to support the wish to segregate, and yet we annually build new segregation campuses without a shred of evidence to support such - zero, none, nil - and yet the doubt, planted by the fear mongers among us, is enough to keep the oxygen pumping into the life of an otherwise dead, morally and scientifically "bad idea" - segregation based on a desire to rid the population of "the unfit"².

In the 70's, Americans particularly, but other nations too, began to legislate around integration and more recently around inclusion. Law is one of the noblest of ideas created by civil society³ (however lawyers have taken a beating in the popularity stakes since trivia has replaced substance in much of what the occupation now addresses) and yet, in determining moral coherency, can we legislate that one person must love, or act out of love towards another person? Certainly, we have enacted some noble laws that speak to inclusion over the past four decades. Starting in the 70's with American Public Law 94-142⁴, there have been several pieces of national and international legislation that brought us closer and closer to embodying the principles and assumptions that underpin inclusion. Large among these, in Australia in 1986, the DSA enshrined integration as a cornerstone principle. When it was deemed not powerful enough, the 1992 legislation of the DDA was enacted and when it too seemed too weak, the 2005 "Standards" were developed. Each of these Australian documents walked us a significant way towards enshrining inclusion. But did Australian society walk *with* its laws towards actually being more inclusive? State laws and education policies conformed. In many cases, however, there has been a reluctance and, in some, outright disregard for the spirit of these legislations. Consider for a moment the fact that multi-millions of dollars are spent in human services today - 21 years after a *New Direction* was legislated. These dollars are spent *primarily on segregation*.

In the early 70's, as a young, *recovering American* with legal advocacy in my blood, I thought that we needed to merely change a few laws, set a few precedents and in 5-10 years, inclusion would be the mainstay offering to children and their families. So much for youthful exuberance! In courtrooms around the world, we soon discovered that courts do not seek truth, science or moral pathways. Instead, “sides” are chosen, strategies are developed, mud is dug up, issues are confused and a fight to the death is the order of the day. Justice, that lovely concept we learned about in school, is a spirit mostly lost in the battle of and for power. We learned that “force” was not going to be with the weaker party. Some of us also learned that forcing someone to take a student they obviously didn't want was not really going to achieve the loving relationship we wanted to present them with in the first place. Laws cannot produce love. Politicians cannot enact love. Law and politics CAN get in the way. They CAN promote inclusion, but they are concepts that cannot be mandated. So a few decades ago some of us decided inclusion was not achievable through the legal institution alone. We still believe inclusion is every child's *right*, yet we know seeking “rights” is the wrong pathway – at least for us.

Demonstrative Advocacy

In the early 80's, I began to reconceptualise what might be a more coherent pathway to meeting our children's need to belong. I came to some realisations that the shift from segregation to inclusion in the treatment of labelled children was a much bigger “project” than those in the inclusion movement seemed to think. I began studying the history of treatment of people with labels and the history of social change movements. Our examination of the history of others seeking to be rid of segregation led us to see that many social changes towards inclusion begin one person at a time and engaged in *demonstrating what one wants* rather than fighting against what one does not want.

Rosa Parks, an American woman deemed to be of “second class”, was one day too tired to sit on the back of the segregated bus. She took a demonstrative action – not in violence against anyone. She wanted to sit in the front of the bus - so she sat down. Who would think that such a simple act would cause such uproar? So began the Freedom March towards inclusion for this group. The young Americans, who rode south from colleges in the north to support Rosa and the movement towards inclusion, stepped off the buses well knowing that the dogs and clubs would meet them with violence. They knew and prepared for the pain they would endure – and they bravely and peacefully stepped off the bus. Ironically, they were called freedom fighters. They loathed fighting; yet our language is limited in describing standing assertively, opposed to something wrong and in favour of something right. Martin King said:

*segregationists probably think that they are right in their methods from the cradle to the grave, it has been instilled in them they have been taught these things their parents probably taught them that; the schools they attended taught them that; the books they read, even the ministers, often taught them that; and above all the very concept of segregation teaches them that.*⁵

Like those who were segregated for the colour of their skin, preachers too taught eugenics as if it were God's word⁶, our children were labelled, our schools segregated and, in so doing, we taught a generation that segregation was the right thing to do. In developing demonstrative advocacy, we took our lessons from Martin and Rosa, learning the incoherency of using the “violence” of confrontational law to bring what is essentially an orientation towards love and forgiveness to a child or a group of people, and thus our journey has been one of developing a

form of advocacy which we have called *demonstrative advocacy*.

Its research question is simple: if violence begets violence, can peace beget peace? The core of demonstrative advocacy is a search for opportunity to demonstrate what it is that we are thinking might be “good” at three levels: -

Demonstration	Change strategy
1. Technically “good” for the children in terms of their development	Pedagogically what schools are probably supposed to be about at the level of science. Demonstrate that all children CAN learn well and together.
2. Morally and technically “good” in teaching children how to get along with one another throughout their developmental years.	Likely the best chance of healing the wounds of eugenics – longer-term, multi-generational, social change strategy.
3. Morally and technically “good” in teaching parents and teachers (and others) how to work together in partnerships	Likely the best chance of healing a relationship long in tension. Both morally sanctioned and technically verified as major contributors to children’s development.

What is the “work” of demonstrative advocacy?

Our search is to find receptive places to “demonstrate” and then work with and show how to transact inclusion, one child at a time, one teacher at a time, one collective or school at a time – whatever it takes, for as long as it takes.

In the early years of this movement, parents moved from fighting legal battles to preparing for peaceful demonstrations. Parents would enrol their children in classes only to have them “grouped” special for part of the day. Parents, prepared in the ways of demonstrative advocacy, would quietly and peacefully say to offers of segregation, “No thank you.” They would not sit in the ‘closets’ of the school any more. These early parent leaders would calmly remove their child to home instruction for the hour and return the child the next hour. They faced angry teachers waving duty of care cards. They faced angry psychologists waving their IQ tests. They faced threats of legal action for merely refusing segregation and yet, like Rosa, they never struck back when threatened. Instead they thanked the good teachers, sending them flowers and writing to their employers when they saw steps in the right direction. Over these last decades many thousands of parents have stood on these front lines globally. Many have changed schools. Some have used force and sadly many have lost a significant chunk of their lives in doing so. Others, by saying *no thank you* to segregation and helping others to demonstrate what they want have been able to establish “islands of demonstration of what is possible, in a sea of segregation”.

Changing the mind of society is not an easy pathway. It is not a placid one. It is a deliberate action requiring much sacrifice, preparation and strategy. Many mothers have voluntarily forgone their own careers to become advocates of this calibre. Several decades of such advocacy have led us to the belief that it is coherent in its match of moral will to model action. It is, however, not for the faint hearted.

In the examples of Esperance (see articles in this issue), we see a coming together of several

of these parent leaders with their school communities and educational leaders to embark upon a community-wide, capacity-building endeavour towards inclusion. The example of Esperance allows us to examine these phenomena at one community at a time.

What are the core ingredients?

Development at the home level

Over the last three years, several of the families (whose stories appear in this issue of *Interaction*) have worked to establish home-based demonstrations of the power of adding an additional critical milieu to the developmental potential of their children who are not developing well, as a front line, sustainable response to the impairment, delay or social perception of their child.

Considering that the child's major brain development occurs most rapidly between birth and 10⁷ and that over 50% of this critical *time* is spent almost exclusively with families, it seems prudent to demonstrate the power of enhancing this relationship as early as is possible. Considering that teachers, children and families together make up over 80% of the variability that determines quality of development⁸, it seems sensible to work across the two most important milieus. Working with home, as early as possible, not only allows us to demonstrate the effects of tapping into early, comparatively larger synaptic development, it also allows a growing of the parent in learning a non-confrontational form of advocacy.

A critical piece we promote is called the 90:10 rule. We made up this guiding rule when we discovered that, once children commenced school, so much time was being diverted to IEP's, discussions of behavior and which program to run, parents quickly lost sight of their role in their child's development. At best, schools allow us 15,000 hours in front of teachers. Parents do this time with their children's alert hours before the child enters school. Continuing to capture a small piece of this time is, over time, an essential aspect of this model. It does go against the grain of our ever-increasing trend to place children in child-care. It is not meant to require this sacrifice; yet we realise that it often does. It should be noted, however, that of the Esperance example, only one parent is "stay at home" and she has a newborn, so maybe it doesn't count? These families have "found a way" to balance their lives to give to their children AND fulfill at least a part of their need for careers.

Development at the community level

Having developed several home demonstrations with a critical core of families with a wide range of presenting issues and family backgrounds, we then began working to develop and demonstrate the positive effects of collaboration across milieus of home and school. Teachers, support and administrative personnel of local and State structures were invited to participate in exploration of the issues of societal moves towards a more inclusive society. Parents who have not been a part of the early participatory projects were also invited to participate. At first, parents and teachers chose separate workshops because they perceived a different set of needs. They also perceived a tension. We used this tension to explore working together. Some of the parents are also teachers. This helped to break the ice. They approached their schools and secured the help of WA's Department of Education via an incredible advocate and educator, Anjie Brook, to jointly host forums. These forums are now in their third year. Many more teachers and parents have come to community-building forums than we had thought in such a small community. Sessions of 50 are now not uncommon. Each forum chooses its next topic: the last was "behaviour"; the next may be "assessment". It is early stages but our view is that

each forum brings schools, family and community closer together in their comfort zones in working with one another and understanding each milieu.

Development at the school level

Following the larger workshops, some individual parent-teacher and school support “teams” have undertaken particular explorations of the applications within their schools and classrooms. One primary school has hosted a conference for teacher aides from the region, invited parents and ourselves to talk with groups of children in open forums about teasing, problems of impairment and how we can work together. Children from these schools email us now with feedback and further questions as their growth in understanding and comfort grows. Another school is exploring the impact of segregation on “giftedness” and seeing what inclusion might offer to this understanding. Again, it is early days. Much work to continue these efforts will be needed. Yet, had we not worked one parent at a time, one teacher at a time, one school at a time, we could not have reached the point of one whole community – this time.

The example of Esperance is not so much something to copy but something to inspire and give hope to those in other communities that demonstrating together, one child or one school at a time, CAN make a difference to a whole community.

¹ Galton, Francis Sir. In *Natural Inheritance*. London: Macmillan, 1889; first conceptualised eugenics. American psychologist Henry H. Goddard's later introduced Binet's IQ test in the United States and was hailed by contemporaries as a major advance in diagnostic technique. With it, he 'discovered' the *moron*, who was believed to suffer from a mild type of mental deficiency that had previously been unidentified: - “moral imbecility”. But Goddard had actually glued his new classification onto an older tradition that was based on social judgments about what constituted normal behaviour creating the appearance in 'scientific' confirmation of what was really a socially constructed prototype. See also “Not Simply Bad and Incurable”: Science, Morality, and Intellectual Deficiency. Steven A. Gelb. *History of Education Quarterly*, Vol. 29, No. 3 (Autumn, 1989), pp. 359-379

² The target of the eugenic movement was broad in terms of individual human differences. Victoria Woodhull Martin (1838-1927) in *The Rapid Multiplication of the Unfit* (1891, pamphlet) stated: “The best minds of today have accepted the fact that if superior people are desired, they must be bred; and if imbeciles, criminals, paupers and [the] otherwise unfit are undesirable citizens they must not be bred.” In Perry, Michael W. (Ed.). (2004). *The Pivot of Civilization in Historical Perspective: Education for Women, Race Suicide, and Feminism*. Seattle, WA: Inkling Books

³ Wolfensberger, W. (1976). *The limitations of the Law in Human Services*. CAMR.

⁴ PL94-142, brought into being in the early 70's, was a landmark law beginning to secure the right of labeled children to go to public schools. It was fatally flawed around the notion of “least-restrictive environment”; a concept that Taylor later debunked but has continued to form the common thinking service design that perpetuates segregations.

⁵ Martin Luther King Jr. (1968). *I Have a Dream: The quotations of Martin Luther King Jr.* Grossett & Dunlap, New York.

⁶ Rosen, C. (2004). *Preaching Eugenics: Religious Leaders & the American Eugenics Movement*. Oxford University Press.

⁷ Bennett A. Shaywitz, Kenneth R. Pugh, R. Todd Constable, Sally E. Shaywitz, Richard A. Bronen, Robert K. Fulbright, Donald P. Shankweiler, Leonard Katz, Jack M. Fletcher, Pawel Skudlarski, and John C. Gore. (1995). Localization of Semantic Processing Using Functional Magnetic Resonance Imaging *Human Brain Mapping*, 2, 149-158. See also Simos PG, Fletcher JM, Foorman BR, Francis DJ, Castillo EM, Davis RN, Fitzgerlad M, Mathes PG, Denton C, Papanicolaou AC. (2002). Brain activation profiles during the early stages of reading acquisition. *Journal of Child Neurology*, 17, 3, 159 - 63

⁸ Hattie, J. (2003) Teachers Make a Difference. What is the research evidence? ACER. (Professor Hattie's synthesis of 500,000 studies of the positive effects on learning.)

Helping Systems to Change: the Example of Esperance.

Robert L Jackson, PhD¹

Abstract

The transformation to inclusive education as a real choice for parents in Western Australia has been relatively rapid and with disputation kept to quite low levels. One of the best examples of this change has been Esperance on the southern coast of the State where real partnerships have been built and wonderful stories are emerging of life-changing inclusion and long-term relationships forming between children with disability and their regular class peers. This did not happen by accident but rather was due to the efforts of a large number of people over many years. In this paper, the key elements are analysed with the intention of drawing a roadmap for others who have not been so fortunate in gaining what should be a birthright for every child – a place at the local school with other children from the neighbourhood.

Early History

The history of the education of children with disability in Western Australia is as dark as it has been in most areas of Australia. Up to 1976, children with significant intellectual disability (classified as ‘ineducable’ or ‘untrainable’) were denied entry into ANY school – special or neighbourhood. Classification was by IQ score with no notice taken of the child’s skills or capacities. The parents were responsible under the Education Act of the time to provide appropriate education for their child, with the Education Department legally entitled to ensure that parents were doing a good job. Children deemed to be educable (with a moderate or mild level of disability as determined by intelligence test) were allowed to go to completely segregated special schools or, in regional areas, may have gone to a special class at the local school. There were even special schools by type of disability with ‘blind schools’, ‘deaf schools’ or schools for ‘spastics’.

To move from this situation to the current one in Western Australia, where children with a disability are increasingly welcomed into neighbourhood schools, is indeed a major transformation. Two items seemed to have been very important in commencing this process of change. One was a parent group called ‘Watchdog’ that took up the issue of education of all children as a right and, together with other emerging advocacy groups, succeeded in getting the law changed. The second was a natural advantage of Western Australia in having large numbers of small rural and remote schools. In most of these areas, it wasn’t feasible to have a special school so many children went to their local school with their siblings and neighbours, and of course the schools

¹ Bob Jackson is Adjunct Associate Professor of Education at Edith Cowan University and has been involved in the education of people with disability for over 30 years. The area of research for his PhD was implementing system change.

coped. Indeed some of the best examples of inclusion worldwide at that time could be found in outback WA and Queensland. As a result of the success of this reality in country areas, it was not possible to deny that successful inclusion of children with a disability was achievable – it was happening in the Department's own schools as well as independent schools. Following the change in legislation, children were increasingly taken into segregated schools although it was another five years before children with multiple disabilities were given access to any education. Inclusion was still denied in all but the regional and remote schools, although some principals of the time did allow children in as special cases on the request of parents. Unfortunately, one of the outcomes of the move to educate all children was the building of more and more special schools in regional areas, so some children who had previously been included were now placed in segregated schools whether their parents objected or not. In fact, the new Education Act made it clear that such decisions were the right of the Department.

In 1986, the Commonwealth Disability Services Act (CDSA) was passed and in 1992 the Disability Discrimination Act (DDA). Both of these Acts set out the goal of integration of people with disability, with the DDA making it illegal to deny entry to a child into regular education on the basis of having a disability. Further, it was a requirement under the Act that all necessary adaptation or support to make this possible had to be carried out or provided, with limited scope to deny this right. Parents started to take cases to the Disability Discrimination Tribunal or their State equivalent with limited success. Normally, the process took at least two years and, even if successful, parents found that their child's education had suffered significantly and what they were eventually left with was still unacceptable. Nevertheless, it was becoming clear to the Education Department and the Minister that the pressure was not going to decrease so they set up a 'pilot project' to investigate the implications of inclusion. They provided 'official' support for up to fifty children to be fully included in mainstream with the project to be independently evaluated by a university academic. The project was also used to take pressure off the Department and Government, with the parents who pushed the hardest being most likely to get a place on the program, although the applications far exceeded the available places.

The National Council on Intellectual Disability (NCID) also played a major part by organising an Inclusion International Conference and the journal *Interaction* printed special editions on inclusion, keeping the pressure on Australia-wide. In particular, NCID published the 'Report Card' where parents and teachers rated their State on how well they were doing on inclusion. Even though this research was unfunded and methodologically fragile, it was politically very powerful as Ministers saw how their State rated in comparison to others. The WA Minister of Education was reliably reported to have said: "I'm not having our State scored as 3 Ds".

The move to inclusion

The review of the inclusion project received a glowing report from the Edith Cowan University academic. Inclusion was found to have benefits for the child with a disability, the other children in the school and the schools generally. Teachers were enthusiastic about the inclusion of children with disability if they were properly supported. The then (Liberal) Minister of Education reduced the difficulty for parents to challenge enrolment, implementing a semi-independent appeal process. The new (Labor) Minister of Education, the current premier of WA, took the process further. He had reportedly had some experience of inclusion through his daughters sharing classes with children with a disability, but was also conscious that many of the processes used by the Education Department at that time were contrary to the Commonwealth

Disability Discrimination Act. This then was a major advantage in WA. We had bi-partisan political support for inclusion and the right for parents to choose the appropriate education for their children.

The next step was a critical one. The Minister commissioned a report into the education of children with disability in WA. To the enormous credit of the local Education Department, they made a decision to have this report as a real investigation of all aspects of the education of children with a disability and to ask broadly for input. Most importantly, the various subcommittees had wide representation and actually listened to and incorporated a great deal of the feedback they received. The resulting report was soundly based and widely respected with clear strategies for making all the parent choices a reality. The Government put several million extra dollars into education for the implementation of the new report, in support of recommendations for in-service training of teachers and support for schools.

As part of their acceptance of the recommendations of the report, the Education Department set up an action plan with a set of goals around preparing teachers and schools and providing the necessary support. The 'Special Education' section was renamed the 'Centre for Inclusive Schooling', with support staff and visiting teachers to assist schools with the inclusion of children with disability. This is currently being developed further with each school having a position of Learning Support Coordinator to support teachers in the inclusion of ALL children, not just children with a disability as it was accepted that there were many additional children not currently being well included due to ethnicity, behaviour, learning disability or lack of literacy or numeracy skills.

The Esperance example

In other papers in this issue of Interaction, developments in Esperance are documented showing that when partnerships are formed between teachers, parents, principals and Education Department support staff, wonderful outcomes are possible. However, this did not happen by chance and it is worthwhile attempting to document what appeared to be key steps in the process of change.

The first point is that the change would not have occurred without the efforts and sacrifice of many families and other individuals over the previous three decades. The changes occurred through lobbying of politicians and bureaucrats, pressuring for changes in the laws and ultimately taking legal action under the laws — usually at the cost of their own child's education. Many of these families would not see themselves as leaders but, in fact, by their actions and examples they have inspired a whole generation of families to believe that inclusion was both right and ultimately achievable.

Political Leadership was another key ingredient. As mentioned earlier, both political parties had listened to families and instigated changes to make inclusion a reality. They not only gave approval for the process to occur, but backed it up with a *real* review and supported the recommendations to ensure that they came into operation. Having this bi-partisan support at the highest levels gave great confidence to parents and others who were looking to achieve real inclusive education as a choice for all children.

Parent Leadership was possibly the single most important aspect of change. Parents in our society are seen as having the ultimate legitimate role in the well-being of their children, so a request for an inclusive education coming from families cannot be as easily dismissed as might

be the case if it was argued by advocates, professionals or academics. From the 1970's, parents have been at the forefront of the movement for change in education and it is impossible to see the changes occurring without this leadership.

In Esperance, the parent leadership has been both very strong but, most importantly, very wise and strategic. In the first stages, networking was used to bring the Parent organisation PLEDG to Esperance to work with individual families on accelerating the development of individual children. This developed over time into a local chapter of the group (PLEDGE – Parents Learning and Educational Development Group, Esperance). Key members of this group realised quite early that inclusion was a key component of their child's continuing educational development, so they organised parent workshops where experts in inclusion were brought in to explain what inclusion meant and why it was important for all children to be included. These workshops seemed to build up a constituency for parents to be interested in and desiring inclusion, which provided the basis for later developments.

After the initial workshops, a conscious decision was made to develop partnerships between teachers and parents. Rather than having workshops focussed around negative aspects of failure to include, teachers who were supportive and successful with inclusion were invited to co-present with parents. This had multiple impacts: it showed parents experiencing less than ideal inclusion; that good inclusion was possible; it modelled the benefits of partnership to other parents and teachers; and it gave positive kudos to those schools and classes where successful partnerships had been formed.




Another development with the workshops was to invite senior members of the Education Department to also co-present at the workshops. There were several very impressive people involved who saw inclusion as much more than just a job and were highly supportive of helping parents and teachers to make it successful. The Education Department had been developing a series of policies and support frameworks around inclusion, which these staff were able to pass on to both parents and teachers. As a result of the involvement of senior members of the Education Department, many more teachers and principals started coming to the workshops with several of them being influenced positively towards inclusion. From this, several teachers and principals made the decision to try and bring in more inclusion as a benefit for all children, and requested help both from the Education Department and PLEDGE. This opening up to partnerships within the schools between school staff and parents had the effect of rapidly improving the quality of inclusion as ideas and expertise were shared between parents, consultants and teachers.

Other actions taken by the PLEDGE group had very supportive impacts. Letters of commendation were written to senior members of the Education Department extolling the qualities of the senior staff from the Department who had been so supportive of developing partnerships. Parents were encouraged to not only express appreciation to teachers for their efforts but to also pass this on to their principal, in writing if possible. It was a very good example of how positive input builds partnerships, whereas complaining or just saying nothing tends to weaken relationships.

Of course, it is early days yet and this is a small beam of light in comparison to many years of darkness in WA's education system. However, when you see real relationships forming, the expression of values such as tolerance, compassion, assisting others and general acceptance of all people in the school, it is easy to believe that the Esperance example will be hard to stop.

In summary, several key aspects seemed to have combined to produce very positive effects. The first was leadership and perseverance from families over many decades. Second, there was leadership at the political level and from within the Education Department. Third, there was a process of education so families and teachers had an opportunity to learn about inclusion and question how it could work. This education was high quality, extensive and over a long period so that thinking could develop. Fourth, there was an emphasis on partnership-building based on the belief that inclusion will work best when we work together. Finally, the process was extremely positive with the emphasis on acknowledging inclusive efforts, in writing and to high levels, which has had the effect of both supporting what is happening and safeguarding against loss of momentum.

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Building inclusive schools through building positive relationships

**Anjie Brook, Principal Consultant, Inclusive Education
and**

**John Hesketh, Student Services Area Manager
Department of Education and Training, Canning Education District**

Impact of the law in promoting change

The Disability Discrimination Act (1992)¹ and the resultant DDA Standards for Education (2005)² have impacted significantly on the educational opportunities for children with disability in government schools.

In the last decade, changes to policy and legislation at both a State and Federal level have challenged Government departments, non-government agencies and private institutions to review their current policies and practices to ensure their compliance with non-discriminatory legislation.

Over the last 100 years children with severe disability have had difficulty entering mainstream education. Increasing awareness and understanding of disability and its impact on communities and family life have gradually forced Governments to re-examine the exclusionary nature of many of their strategies. Governments and international agencies have reflected upon and highlighted the rights of children with disability alongside the rights of all children.

The 1992 Disability Discrimination Act (DDA) and the consequent DDA Standards for Education continue to have a significant impact upon the educational opportunities of all children, not only those with clearly defined disabilities. The DDA has also promoted the questioning of policy and legislation at both State and Federal levels across the board, ensuring a complete review of these to ensure standard compliance.

From legislation to implementation

Legislation is one thing; changes in public perception and tolerance are another. Clearly, the Federal decision to enroll children with a disability into a mainstream classroom has a much wider impact than the mere integration of a special education curriculum into a mainstream classroom. Inclusion and inclusive practices impacts upon all children and allows each child to be accepted within their home school on the same basis as every other child,

The task was large, not everyone was happy, and it became abundantly clear that not all those expected to be in favour, were so. Interestingly many parents of children with a disability were just as afraid of the emerging model as parents with mainstream children.

In 2002, the WA Department of Education and Training (DET) undertook a comprehensive review of educational services for students with disability in Government schools. The findings of this review are detailed in the report titled *Pathways to the Future*³. The report identifies twenty recommendations to improve the opportunities for children with disability enabling them

to access and engage in a challenging curriculum where they can learn with their age peers at their local neighbourhood school.

A key initiative of the review was the Building Inclusive Schools strategy. This strategy was designed to increase the awareness for, and understanding of, inclusive school development for school leaders. This strategy was based on the seven principles on inclusive education described in the *Pathways to the Future* report and reflected the philosophy and principles of the *Curriculum Framework*⁴. The professional learning program supported school leadership teams to discuss and explore the concept of inclusion, reflect on responsibilities outlined in policy and legislation and provide resources and materials to support leadership teams in developing inclusive school cultures, policies and practices.

To further support inclusive school development, the Building Inclusive Classrooms strategy was initiated in 2005. The strategy was designed to raise the level of confidence of teachers in addressing the needs of students with disability and learning difficulties and to develop school procedures and processes that support the development of inclusive school cultures (Pathways to the Future, 2004).

Schools across the State were provided with financial resources to enable the position of a Learning Support Coordinator to be created. This specialist teacher role was designed to work alongside class teachers and education assistants to develop and implement appropriate teaching and learning adjustments that allow students with disability and learning difficulties to engage in a challenging and rewarding educational program that maximizes their learning outcomes.

Training for inclusion

All the Learning Support Coordinators (LSCs) from all schools across W.A. participate in a two-year professional learning program that provides them with skills, knowledge and understanding to support class teachers in differentiating the curriculum, model effective teaching strategies and to facilitate Learning Support Teams in each of their schools.

DET appointed four Principal Consultants, Inclusive Education to lead this strategy across the State and to manage the district based Inclusive Education Teams. These teams support the LSCs with their training and role implementation in the local school context. These positions, along with and the formation of the Inclusive Education Standards Directorate, demonstrate the commitment being made by DET in the continual development of inclusive school environments.

Working together

Another major strategy for the implementation of the review at the local level was to improve coordination between key Government departments in supporting the needs of students with disability. This resulted in an active Memorandum of Agreement between DET and the Disability Services Commission (DSC). The focus of the memorandum resulted in improved and consistent communication with parents and carers of children with disability. This informed them of their rights, their increased educational opportunities and described the provision of support available for their child through DET as well as providing a coordinated service from the two agencies.

The strategy, in the first instance, focused on informing parents of children with a disability of changes to legislation, examining the impact upon the practices of teachers such as enrolment, the day-to-day operations in Government schools and the means by which DET was complying with these changes. Parents indicated they were keen to understand and be party to the new

opportunity of choice but wished to discuss the most appropriate educational setting for their child in deciding whether this should be a local neighbourhood mainstream school or a supported educational centre or school. Parents also indicated they were keen to understand changes of the mechanisms of resource allocation. The mechanism, *Schools Plus*, for the first time, focused on the individual needs of a child with a defined disability and provided appropriate funding to the school to address the needs of the child through extra teacher and education assistant time.

The education community responded to the demands of parents backed by legislation in different ways. Proactive partnerships between DET and DSC have developed a shared common goal of improving the knowledge of parents and teachers regarding inclusive education and celebrating positive inclusive practices. Parents are invited to workshops alongside teachers, education assistants and principals to discuss and explore the recommendations described in the *Pathways to the Future* report and further develop the other strategies DET requires to employ in order to address its recommendations. Such workshops also provided opportunities for parents and teachers to share examples of inclusive practices and present both positive and negative stories regarding inclusion so that positive collaborative partnerships between parents and teachers can be developed and barriers overcome, leading to improved outcomes for all students.

Joint workshops also provided an opportunity for discussion and debate of the issues that teachers, schools and families face in developing inclusive cultures and provided assistance in translating this to effective inclusive classroom practice. Opportunities at the workshops were given for voices to be heard and questions responded to by managers and support staff from DET, parent advocates and recognised experts in the area of inclusive education and Local Area Coordinators from DSC.

In the Esperance Education District, a strong parent network, PLEDG(E), became aware of the work being carried out in the community by the Canning Education District and negotiated with key DET managers to support them in developing and facilitating similar workshops with parents, teachers, education assistants and principals to celebrate and debate inclusive education.

The parent group developed a strategic plan in response to their desire to raise awareness of inclusive education practices and to highlight how successful partnerships between parents and teachers impacts significantly on the improved educational outcomes for all students. The workshops were facilitated by parents and invited teachers to share their inclusive practices with the group. The workshops have been addressed by inclusive education researchers and recognised experts in the field of inclusive education and also managers from DET.

The workshops not only provide an opportunity for celebrating and sharing inclusive classroom practices but also provide an opportunity for both parents and teachers to openly discuss the issues and concerns for all students and the school community in the development of inclusive school cultures and practices. This open and honest approach allows for the questions and queries from both school personnel and parents to be discussed and explained.

The workshops provided a forum for teachers to gain improved understanding and awareness of the issues parents face in striving for the highest educational opportunities and outcomes for their children. The workshops equally provided an opportunity for parents to gain improved understanding and awareness of the work issues and demands classroom teachers face in schools today.

DET continues to maintain a strong focus on developing a shared understanding and commitment to the principles of inclusive education by all members of the school community. It is through the continued provision of opportunities, such as those provided in Esperance, that will ensure a shared understanding of the issues and concerns of parents, teachers, education assistants and principals.

Changes of immense magnitude that have an impact upon all facets of the community cannot be instigated without their involvement. Inclusive lifestyles require the teaching community to be onside and have their needs understood and addressed. The parents of “mainstream” students need reassurance, school administration needs support and a little bit of persuasion now and again, student support services need redirecting, bus drivers, local councils and shopkeepers need re-educating. The barriers of inclusive school development need to be honestly identified and addressed and successful inclusive practices of schools celebrated. By building inclusive schools, we build inclusive communities of today and for the future.

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Joshua

by Grace Brotherton

Presented at
Parent Learning and Education Development Group - Esperance
Inclusion Workshop
Introduction and Problem Solving
15 August 2006

I am the mother of two beautiful boys. My eldest boy is nine years old and my other son is six years old.

My eldest boy Joshua has *cerebral palsy*. My partner and I were told when Joshua was 9 months old. We were told that he had very *low tone* and that things were not developing as expected.

I went into 'fix it' mode.

We were sent to different specialists. At this stage, we were living in a country town called Katanning in Western Australia. We ended up going to a lot of appointments in Perth.

We eventually had assessments done with the *Cerebral Palsy Association*. We were placed in a therapy program, which was organised to liaise with Katanning therapists. We started the therapy with volunteers who came to our house to help Joshua.

We later moved to Perth so we could access more therapy services. After we moved to Perth, we started looking into a combination of special education and mainstream schooling.

While in Perth, we started going to workshops on inclusion run by Bob Jackson¹ and Darrell Wills². We found their research and information quite startling to say the least.

We believed that venturing down this path of inclusion was the best benefit for our boy to help him fit in with his peers, be able to live happily in the community, hold down a meaningful job and for his own wellbeing.

I have faced the question, "What is wrong with your son?" on quite a few occasions. My reply is, "Nothing is wrong". He certainly has his extra challenges. But his greatest attribute is that he is highly qualified in being able to manipulate people – especially adults.

I believe one of the most heart breaking things that we can come up against is to be told where your child is not up to. I don't believe that when we are dealing with our kids with extra challenges, we are that naïve about their progress. What we need is to look at the areas in which we are working and realise that the achievements can sometimes be quite small. But it is happening.

¹ Dr Bob Jackson is an Adjunct Associate Professor of Education, Edith Cowan University; Managing Director, Include Pty Ltd.; Chair, Foundation for Social Inclusion (Inc).

² Darrell Wills is the Director of the Parent Learning Education Development Group (PLEDG).

This can be one day at a time. When you are living with children with extra challenges, the end of the rainbow can seem a long way away.

I believe that sometimes we are so involved with trying to find out what the diagnosis is for our kids, that we can lose sight of just doing the ordinary things in family life. Which is just as beneficial for our kids' development.

We have a great desire for our boy to be included in all aspects of community life, whether this is in Esperance or wherever he chooses to live.

We believe that having people treat Joshua as other nine year olds is most important. It is not questioning what he are capable of, but just letting him fit in and helping him achieve his goals.

When we come up against what we believe is inappropriate behaviour from our son, like socially not doing as his peers, we find being told by others that *he is fine*, or *he is such a lovely boy*, *don't you worry* that, in the long run when Joshua is an adult, this behaviour will not be appropriate, so we cannot accept it now.

Our boy has a delightful nature at being able to love everybody — persons, all creatures and bugs in this world. I believe that if everybody could capture even a little of this nature, we would probably be a lot *cruzier* and relaxed about life.

I believe in the basis of inclusion.

Our kids can be thought of as being very different. But they have just as great a desire to fit in with everybody else and to be accepted. I see the beautiful qualities that come out in our son's peers in their caring and supportive nature.

And I believe that broadening our knowledge on this with the likes of Darrell and Bob is a great asset to us all.

My Son

by Janette Fletcher

Presented at
Parent Learning and Education Development Group - Esperance
Inclusion Workshop – Reading
31 October 2006

I would like to share my story about my son who is now 11 years old.

His birthday is late in the year and after only two weeks at Kindergarten, it was suggested to us that he repeat Kindergarten the following year. He was very happy at Kindy and liked being with other kids so we let him stay at Kindy and he repeated the following year.

We read to him every night when he was young and still do now, although only occasionally as it's not "cool", but he still has a great love of books. As parents, we knew that the more we exposed him to books the better.

He is very outgoing and friendly but has always struggled with his school work. His first couple of years seemed to pass without any cause for concern. Teachers said he was unable to sit still, was very active, lacked concentration and had poor organisational skills; but his reading and writing was at Year level. Everyone seemed to want him to sit still, but we knew that this was impossible! We religiously did his homework with him and tried to get him to read to us, but we really struggled with it.

His report at the end of Year 3 showed he was now below year level in reading but we were reassured by his teacher that he would 'catch up'. "*Just keep reading to him and getting him to read to you,*" they all said. We had many arguments and fights trying to get him to read but no one could give us any more tips about how to improve his reading. We realised something was not right when our younger daughter was able to read so well and confidently and breezed through her school work.

We did however have many health professionals trying to tell us what was "wrong" with him. We went to *occupational therapists* to try to improve his balance and coordination; we saw *paediatricians* concerning his behaviour and wanted him to go onto medication; we did a program called *brain gym* where the whole family was involved; we tried changes in *diet and vitamins*; and even *flower essences*! There was no end of people trying to provide the magical solution. We were even told he needed *coloured glasses*!

My partner and I knew that our son was no slouch. He can name every ocean fish from Perth to Esperance and beyond, and has the most amazing memory. He remembers things I don't (although that may be my age catching up on me!).

Teachers were unable to give us any extra work or information that would improve his reading skills and they started to focus on his poor behaviour. By Year 5, he had a serious aversion to reading and was spending a lot of time on the bench outside the classroom at school. It was a fight to get him to read anything to us and he was now telling us he was 'dumb' and his self-

confidence plummeted. He was bullied at school and on the bus and, for the first time in his life, he told me that he hated school.

As a parent I would have done anything.

I was visiting the teacher weekly, always with bad news and was offered “remedial” reading for my son. At the same time, I heard of Darrell Wills¹ through a friend and of the great work he had done with another child in my son’s class. So I thought, why not, I’d tried everything else!

So at the beginning of 2005 when my son was in Year 5, Darrell tested my son and it was discovered that he was reading at a Year 2 level. I suppose I’d always known that he was a poor reader but to have it spelled out in black and white was totally devastating! He had failed so many times he didn’t even want to try anymore. I then became aware of all the strategies he had employed to try to read, such as looking at pictures, or to get out of doing work he could not do. I knew if he couldn’t read that he would struggle all his life.

Nearly two years later, with lots of hard work by my son and I, and the encouragement of Darrell and Paul Cain², my son now reads at his Year level. His self esteem has grown to new proportions and he now says he is clever, not ‘dumb’. He now reads street signs, advertisements, comics, anything he can get his hands on. He enjoys school and when I ask how school was he says, “wicked!”

I know he is no angel (what child is!). We just wanted our child to reach his full potential and be confident to meet challenges in his life, as any parent would. Without support and skills, parents struggle to assist their children with reading. I hope you take home some skills today to help your children be the best they possibly can.

¹ Darrell Wills is the Director of Parent Learning Education Development Group (PLEDG),

² Paul Cain is an associate instructor at PLEDG.

Our Children

by **Rochelle Classen**

Parent Learning and Education Development Group - Esperance
Inclusion Workshop – Reading
31 October 2006

All we want for our children is for them to be able to lead “normal” lives: to fit in; to make friends; get an education; and develop skills. This will enable them to live productive lives and contribute to society.

Byron was born in 1999 and progressed very well up to the age of two and a half years of age. He reached milestones on or even ahead of the expected age.

During 2002, I was diagnosed with breast cancer and, as a family, we went through a very stressful period. While going through chemotherapy, radiation therapy, my father’s death and a very stressful period for my husband Shawn at work, we did not realise our son was becoming more and more silent, floating into a world of his own.

Our denial caused us to wait until Byron was three and a half years old before we took him to a paediatrician for an assessment.

The word *autism* kept ringing in our ears but, once we accepted the fact that our son was autistic, the road to leading a normal life started.

A specialist in autism assisted us in changing Byron’s diet and enrolling him in an early intervention behavior modification program. It would be a lie to say the road has always been easy but, now, seeing our son laughing boisterously instead of staring at the corner for hours at a time, has made it all worthwhile. I have to mention that we would not have been able to endure without the support of Byron’s grandparents, our family and friends.

I was quite apprehensive about our move from South Africa to Australia eight months ago. But I have been pleasantly surprised by:

- the wonderful, passionate people we met;
- the inclusive schooling system, which lead Byron to mimic normal behavior. (You can clearly see him becoming aware of his own “odd” behavior which he now largely avoids or at least tries to correct.)
- the brilliant assistance from Castletown Primary school and PLEDG-Esperance (including Darrell)

We all have skills of value to society — some educate, some create. At the core of these skills is the ability to communicate.

We have placed Byron on a reading and language program with Darrell to assist with his ability to communicate. He is progressing surprisingly well and shows a great sense of accomplishment when successfully recognising sounds and words. I hope that the ability to read opens up a

completely new world for Byron.

From the anxious moments of hearing that Byron was autistic, we travelled a long and bumpy road to where we are now, accepting and loving our child for exactly who he is.

We have not successfully defined what a “normal” life would constitute, but Byron has shown us what it is to lead a happy, contented life. We would not exchange him for anything in the world, not even a version of himself without autism.

While I have this opportunity, I would like to thank:

- The Principal and staff of Castletown Primary School — especially Mrs. Thorpe, Michelle O'Sullivan and Vicky Morgan.
- Byron's classmates and their parents
- The Community of Esperance
- Parent Learning Education Deveopment Group (PLEDG) — Darrell Wills and Paul Cain
- Bob Jackson — Adjunct Professor of Edith Cowan University

We should all take time to be thankful for what a first-world environment, with inclusive values, really does for our children.

The Country Road To Inclusion

by Annette and Luke Caelli

Parent Learning and Education Development Group - Esperance

Five years ago, our son Jon was born, pronounced healthy and, within a week, we returned to our farm near Ravensthorpe on the south coast of Western Australia.

Jon smiled at the usual age, but from then on his clinic charts started to show a decline. Our first diagnosis came back as likely *cerebral palsy*. The memory of that gut-wrenching day will never leave us. For a few months, we waited for the results of a battery of genetic and other tests to confirm the diagnosis. Our greatest fear was that it may be regressive and that our son would die.

When next we saw the paediatrician, she started with, "I would still be concerned." I gulped and asked, "About what?" "That he may need assistance with his education," she replied in a 'break it to them gently' tone. "Is that all!" I thought, with great relief. The diagnosis had switched to microcephaly, later adding Pervasive Developmental Disorder – NOS (Not Otherwise Specified- meaning *they don't know*), epilepsy, global developmental delay and Autism Spectrum Disorder.

To us, our son remains just Jonathon. With this knowledge, we were driven to focus on the positive. We would seek for Jon the same things we wanted for his sister — to develop his full potential, an education to prepare him for life, and a whole community that would include and support us. We would draw deeply on our love, our faith, and our family and friends to help us down that road.

Eager to direct our energy in a positive direction, we entered via the medical system into *early intervention*. We did speech, occupational and physio therapy. We studied *Applied Behavioural Analysis*. Somehow though, there was still something missing from our approach, which at the time I could only have described as *an ability to live a normal life*. Our efforts seemed to be directed in unnatural fits and bursts.

Before we knew it, Jon was four years old and due for Kindergarten. We had been so busy with medical appointments and therapies, we hadn't really considered education very deeply until then. We were delighted that schools now offered inclusion as an option. We saw many advantages in having Jon raised in a close knit community, educated with his peers and his sister. Other options would not have come close. "Special" schooling was neither proximate to us or, in our view, able to educate Jon to live in our 'real world' community.

We attended a seminar on inclusive schooling run by Darrell Wills. Jon was not yet in school, so we could not pose any actual scenarios and questions, but we were in agreement with what we heard that day and assumed that the education system would provide the type of inclusion

referred to. It was simply logical, or so we thought.

We came away from our first meeting with the school team satisfied that inclusion would be offered and possible. School psychologists, Esperance therapists and the Centre for Inclusive Schooling (CIS) would be available to assist teachers. We drew up IEP's (Individual Education Plans), emergency plans and risk assessments. An Education Assistant was employed to assist in the class. We felt certain that inclusion was normal business and that it would just happen. We had no idea inclusion was so new to schools.

Our first hurdle appeared two days before school – we couldn't get Jon on the school bus. The transport authority not only required the fitting of a harness to the bus but also the employment of a bus monitor. As a Kindy student, he was a *complimentary* passenger, and the authority did not supply monitors for complimentary passengers. We were grateful for the assistance of our school Principal and, after significant lobbying to Ministers, Jon finally got on the bus. Until this was resolved, I drove him 33km to town, stayed the day (to save an extra trip) and then drove him back out.

School itself started off better than expected, with Jon coping well with the change but, unfortunately, things slowly unravelled and the road to inclusion became a roller coaster of staff changes in every support position. By the end of the year, only the Education Assistant and the parents remained constant. The IEP turned from being a working document used to guide teachers in adapting the normal curriculum to one that developed into a separate curriculum of its own, increasingly distant from his peers.

As parents, we had become so used to medical *experts* guiding our moves that we had gradually lost the confidence to make decisions affecting Jonathon for ourselves. Faced with a profusion of specialists, and the new experience of including a child with a significant disability, led his teachers to question their own intuition and experience. The confidence and control they displayed with the rest of the class did not carry through to Jon. This *learned helplessness* had crept upon us all and severely hampered our ability to plan and make proactive decisions about Jon's education together. We were leaving it to the experts – who kept changing the view to *special*. For years, in spite of research to the contrary, we had been led to believe that *special* people need *special* treatment and *special* schools. Freeing our minds of those misconceived notions proved much more challenging for us adults than for Jon and his peers.

If you can't fully include in Kindy, then where/when can you include? We had now spent a whole year of Jon's precious early years trying, in vain, to have him fully included. We did not want to take on a position of the *full inclusion police*, but we wondered just who would? We hoped the new school year would bring a fresh start. Sadly, it only highlighted the problems of the previous year. People looked at me strangely so many times as I restated our desire for inclusion, that I was starting to question my own sanity.

PLEDG (Parent Learning Education Development Group) Esperance was now running inclusion workshops with the Education Department. I went again, hoping to confirm I had the *right end of the stick* when it came to inclusion. When Anjie Brook from the Education Department enthusiastically described the wonders of full inclusion and its availability in WA schools, I nearly walked out in tears and disappointment. *This is so not happening for our school*. Fortunately, I gulped hard and stayed put. I listened to Darrell Wills and Bob Jackson with the benefit of some real experience behind me. It seemed I was on the right track. The

Department's policy position seemed to support full inclusion as the best option morally and educationally. We supported it as parents. The school had told us it supported inclusion, so what was wrong?

I started to wonder that perhaps the problems began at the fundamental level of what we think is inclusion. Surprisingly, the Centre for Inclusive Schooling seemed to offer no definition of its own, so I decided to pose the question to those charged with delivering it at the next case conference. Unfortunately, no participant was prepared to offer a definition of what inclusion meant to him or her. The question came back to me. I said that I want the physical, social and curriculum inclusion referred to by Wills and Jackson. This provoked much debate. Some claimed such inclusion was not possible, others that it was in fact what we had already happening, and us claiming things were still falling short of the mark. We were also told that the Autism Intervention Team would likely hold the answers to our problems.

Accordingly, Jon was to be physically included in areas such as playtime and singing, but when formal activities started he was to be removed from his classmates to do unrelated activities in a separate area. It was at a desk in the far corner, behind a pin-up board. They had decided their definition of inclusion was segregation.

Whilst the teaching staff appeared to be doing their best to keep all sides happy, it broke our hearts to visit school and see our son so excluded, and though we tried to hide feelings, our disappointment must have shown. We decided we needed to take a break on school matters and focus at least 90% of our time on development at home.

We made the decision to join PLEDG and obtain Darrell's assistance. We wanted to fully include Jon at home and in the community, even if it was not possible at school. Darrell came on board, and for the first time we had access to a clear measured assessment of Jon's developmental level, and a logical idea of the steps ahead. Instead of a sporadic and narrow therapy focus, we learnt to look at a wide range of goal areas (e.g. self-help), and to involve Jon more naturally in our life. Gradually we moved away from *learned helplessness*. Sure, we still had access to professional help, but now we did the driving, becoming more proactive, and finding ourselves as parents and *senior partners* again. Jon made incredible and immediate improvements. We not only noticed it ourselves, but others, including specialists commented to us. The link we had been missing was a "normal life". Instead of looking first for modifications, we aimed straight for what we wanted (and succeeded more quickly in achieving the desired end goal). We normalised routines, rules and *life* so that Jon would learn to deal with normal environments, not specialised ones that did not exist in general society. We discovered Jon could use communication cards better than we knew. We kept the cards but ensured we also kept up expectations and challenges with regard to speech. Guess what? – he started imitating some sounds. Though our goal had remained to teach Jon to speak, we had become so focused on teaching him about the special communication aids that we forgot to simultaneously develop the speech itself.

We were quite unsure what to do with our 10% focus on school, fearful of doing more damage than good and very conscious of the pressure on teachers. Two events changed our lives. We were asked to sign our approval on a Behaviour Management Plan that we didn't agree with. We wrote down why. The principal had a much clearer idea of our position and sought to resolve the issues with us. At around the same time, PLEDG Esperance ran an advanced workshop on solving problems within an inclusion paradigm with speakers Darrell Wills and Bob Jackson.

Our principal decided to attend to find out for himself what these guys were all about. He came back from the workshop and proclaimed that the school would now do proper FULL inclusion. He invited Darrell the same week to talk to the teacher and show her what it meant. Again I cried – this time though they were tears of relief and happiness.

Since that time, our relationship with the school is much more open, normative and positive. The desk behind the pin up board is gone. Jon is adapting well to doing activities with his peers and they are working well with him. Jon's school activities are now drawn from the normal curriculum with modification for his developmental level, and he is learning to follow the normal class routines and rules. Before he dealt mainly with the Education Assistant, now it is more balanced with contact with his peers and teacher. The teachers are not fearful to have opinions or ask questions. Issues still arise, but now teachers and parents are more confident to communicate and draw on their own experience and intuition first, whilst still having the option to draw on external resources where and when they feel they are needed. The beauty of full inclusion is that it applies equally to all people and environments, not just to the *disabled*, not just to school. It is so logical you wonder why at times it seems so elusive.

We hope our story will inspire others who seek full inclusion. If it can be done in a small country town on the south coast of Western Australia, then it should be possible anywhere. As Darrell will tell you, it is mostly an issue of *will* and *skill*.

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Joe

by Therese O'Neill

Parent Learning and Education Development Group - Esperance

My son Joe was born with an overgrowth of lymphatic vessels on his top lip. There is no treatment and he remains under the watchful eye of the Princess Margaret Hospital. Whenever Joe is sick or under stress these vessels swell. They do not impede his speech or his intellect. By the actions of others, however, it does affect his self-esteem.

Joe's father passed away when he was two years old.

When Joe started Kindergarten in Kulin, Western Australia in 2001, he changed from a very happy little boy into a very withdrawn, non-communicative, sad and empty boy. The changes were insidious.

I started to get approaches by the school concerned that Joe wouldn't interact when speaking, drawing and participating in songs and games, etc. I was shocked at this time, and remember two or three *heavy* case conferences with a psychologist, his teacher, the deputy principal and a social worker.

I was told what Joe wasn't doing, and at each meeting he seemed to be doing less and less. I think at the last meeting I was told that Joe had tested only 70 for I.Q. and he needed to go into special education. I had known Joe for five years; by then he was my fourth child and I did not believe he needed special education.

There was no pathway for me to see what was happening, as I would not accept the school's assertions. Conflict developed and we struggled on with pre-Primary. What I was able to do was volunteer my presence at the school and support him. During Kindergarten and pre-Primary at Kulin, the bullying about Joe's appearance was very upsetting.

We moved to Esperance in 2004. At Nulsen Primary School, things were more conciliatory. They welcomed my presence in the school and had a clear policy on bullying. They did not exclude him from the classroom and he started an individual education plan. Given his past trauma, we started counseling with a clinical psychologist.

We then moved again and I enrolled Joe at the Esperance Primary School. The school did not accept Joe and I. After the first week at school, I went to see the teacher who went through a huge list of everything that Joe couldn't do. I remember saying to her; "Is there no future for him? Can't you tell me anything that he can do!?"

He commenced *exclusion* during this year, three times a week in the morning. I was allowed to volunteer in the classroom to help my son, to take part in his learning, and to tell him what he can do, that he has a right to learn, and for me to meaningfully help him to find out just where the goal posts were.

The school system - to that point - had failed my son, they had taken away his love of reading, storytelling and being with others. Other behavioural *stuff* started to happen for Joe. He started to refuse to go to school, feign illness and threaten to run away. During this time, his academic work was reaching new lows. He had no interest.

Withdrawal from interaction was Joe's way of coping with exclusion and discrimination. And because he withdrew, because he looked different, because he had "one of those mothers" - which is what I was referred to as - there was no place for him. The impact upon his self-esteem was dramatic.

As fate would have it, there was a PLEDG (Parent Learning Education Development Group) brochure at work. I first thought this was more exclusion and discrimination. My friend Janette had had similar issues, so I met Darrell Wills and Paul Cain and things began to change. He started his reading program and within a short period of time he began reading at, and then above, Year level. Improvement was demonstrated in maths, writing, interaction and self-esteem.

Joe can now see a future for himself.

As the specialist at Princess Margaret Hospital said would happen, his appearance began to change, and he has gained mastery over the essential behaviours that help him learn and, in the short life of a nine year old boy, he went in the tumble dryer and came out intact. If not for the PLEDG program, I really don't know what could have happened.

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Devin

by Michelle O'Sullivan

Presented at
Parent Learning and Education Development Group - Esperance
Introductory Inclusion Workshop
15th February 2006

I am a parent of an eight-year-old boy – Devin – who is in Nicola Rose's Grade 2/3 class at Castletown Primary School. I am also a teacher at the school.

I want to give you a little background information about Devin's journey so far and why I am passionate about inclusion for my son.

Devin was diagnosed with *autism* just before his second birthday. After trying to access intervention for him from Esperance for twelve months, my husband and I decided to move to Perth to be closer to services.

We started working with *ISSADD* (Intervention Services for Autism & Developmental Delay) doing a home therapy programme, which was based on *applied behaviour analysis*.

When it came time for Devin to start Kindergarten, we applied to a special school based at the University of Western Australia. There were only three students in a group at a time and we felt the one on one would benefit Devin. He also attended his local school Kindergarten.

After six months, we withdrew him from the special programme as he was not happy and was picking up some bad habits from the other students. He loved going to his local Kindy on the extra day.

My husband and I decided to try again with a *special* – I don't really like this term – school for pre-primary. Devin attended an *autism* school, again with only four students for two days a week and his local school for three days. This time he benefited from the small class as their focus was to improve the children's skills for mainstream school, and everything he learned was then practised at his regular pre-primary. He still, however, picked up some bad habits from the other three students.

We then returned to Esperance and chose Castletown Primary School for Devin. They have a separate unit at the school and at the time we weren't sure which way we were going to go. Together with Devin's teacher for Grade 1, Wendy Weckert, we set up a separate little area for Devin so that he could do his work while everyone else did things around him. I honestly believed this was the best outcome for him. However, most mornings Devin would cry and scream for twenty minutes, and I would leave in tears.

Towards the middle of 2004, Darrell Wills came to Esperance to give a talk to parents about inclusion in schools. After listening to him, it was like a light went on in my head. This is what I want for my son – "real inclusion".

Luckily, Wendy Weckert was fantastic when I approached her and asked if we could please

change the whole way Devin was included at school. She was happy to get on board. Devin's assistant, Wendy Swann was also wonderful, as she had to also change her way with him as well. She stepped back and let him interact more.

For the remainder of Grade 1, Devin was much happier – he was expected to follow the rules and he did. He was included like everyone else and his self-image improved.

At the beginning of 2005, I was again very nervous. A new teacher. A new class. I told my husband not to expect anything to be done for a month, as I would be busy helping Devin settle into school.

Nicola Rose was Devin's teacher for Grade 2 and he was happy after two days, no screaming, he didn't really want his mum (I thought she was a miracle worker!). I asked Nicola at the time what she was doing to make inclusion look so easy and she summed it up by saying "I am the same to all the students in my class".

Devin has benefited so much from having a person with such an inclusive attitude as his teacher and we have developed a great partnership working together with each other, as well as with his assistant. He now is picking up the good habits of his other class members and following normal class routines.

He is still significantly below his year level in many areas and is in the main non-verbal. However, he is happy, loves mixing with the other kids, works on the class programme at his level and has friends — that is all my husband and I have been searching for.

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Teaching Devin

by Nicola Rose

Teacher - Castletown Primary School

Presented at
Parent Learning and Education Development Group - Esperance
Introductory Inclusion Workshop
15th February 2006

I have been teaching for ten years, at different year levels and with children with diverse needs. However, I believe that all children in my class are *special*, they are all individuals, and they all have their good points and their quirky ones.

Inclusion of Devin, or any other child who has special requirements, is extremely important not only for that particular child but also for every other member in our classroom.

I believe this stems from my own personal experience. I grew up with an uncle who had muscular dystrophy and was confined to a wheelchair. However, this did not stop him from participating in life and being an active member in his community. I believe that having him in my life provided me with an expectation that anyone can really achieve anything and I expect that from the children in my class.

I find it difficult to understand when people ask me, how do I handle having an autistic child or any other child in my class. "Handle?", I always ask, "there is no need to *handle* anyone in my class". As teachers, we are aware that there are always different levels in one class and that is how I approach teaching all children in my class. Inclusion is for the benefit of all children.

Watching Devin come into our class, happy and ready to begin a day at school and watching the other children interact with him, including him in their activities, is fantastic. Ensuring that he is following the class routine and participating to the best of his level is always a positive experience for all.

It has been interesting to watch those who were at first "wary" of Devin in the first few weeks, are now asking to be his partner, read to him and include him in their group activities. Therefore, Devin is being included and the other children are taking it upon themselves to be inclusive.

As a teacher, I do not have to coerce children to include Devin or any other child into groups. I believe that the children have bonded with him and each other and value all the differences and needs not only with Devin but also with others in the class.

Including Devin socially is extremely important, as is his academic learning. I have always believed that inclusion means exactly that. If the class is involved in a maths activity then so is Devin – either the same activity or a modified version to suit his learning needs. Devin is never excluded from the class or our activities. I also employ peer tutoring and never find it difficult to find a tutor. The children are always willing to work with Devin.

The modifications that are made are not difficult or extra, as I always need to make some modifications for others in my class. I also have a child with *CAPD* (Central Auditory Processing

Disorder) and need to meet his learning requirements. An example from last year was a booklet that my class made for our pre-primary buddies. Each child had to write an Aboriginal myth and publish it in a booklet. Devin's project was to make a booklet and to have the sounds he had been learning and practising throughout the term. His buddy in pre-primary loved the booklet.

Other strategies I have used include concentrating on what he can do and use them to the best of his ability. Devin is very good at tracing, which is also good development for his fine motor control. Therefore, during our daily writing activities, Devin traces over letters and sentences. As the other class members are writing, so is Devin. When my students are completing spelling, reading or any of the eight other learning areas, Devin is expected to be included and participate in all of them.

I would like to thank Wendy Swann who is Devin's assistant, as well as mine and the twenty-three other children in my class this year. She provides wonderful support for me and works with the whole class, not entirely with Devin. The children in the class understand that she is there to assist them when the need arises.

Modification is the keyword. It is not difficult to modify an activity to suit the needs of the children in a class. It can be so simple to provide a learning experience that may look the same but can be slightly different to suit the learning requirements for that particular child.

Forming a positive relationship and communication with parents is one of the key factors on the successful inclusion of a child. Michelle and Pete (Devin's parents) have been fantastic, as they have provided support to our class. We have been able to talk to them about any issue that may have arisen and we are able to work together to solve a problem if necessary. But I must make it clear there are more celebrations than discussions.

Being able to talk to the parents about any achievements is always great and beneficial. But you must also be able to feel comfortable to discuss all issues, so they know what is happening in the class with their child, can help with problems, and also celebrate those stellar moments with their child and loved ones at home. Communication with all interested parties is thoroughly encouraged.

Also, don't forget to share successful strategies with peers. As with parents, colleagues may have suggestions and want to celebrate with you.

Overall, I have personally enjoyed Devin being a member in our class. It has not been a daunting or scary endeavour, as he is another child in my class who is just as special as the twenty-three others. He is valued for who and what he will become.

Thank you Devin!

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