# Submission To Inquiry into Disability Care and Support, Productivity Commission

## 1. Authors

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## 2. Our Target Group and Experience of Authors

We work with babies and children (0-18 yrs with permanent brain damage resulting in a physical, cognitive, and/or sensory disability, Eg Cerebral palsy, acquired brain injury or stroke and developmental delay ie Down Syndrome

The Kids Plus Foundation has extensive experience in the delivery of intensive therapy programs (paediatric physiotherapy, occupational therapy and speech pathology), for babies and young children in early intervention, and for school aged students. The therapy programs focus on achieving participation and inclusion for children with special needs, focusing on their basic daily functional skills including mobility, communication, self care, eating and drinking, access to play, access to education, and ultimately to live as independently as possible.

www.kidsplus.org.au

## 3. Who Should Be Eligible

1. It should be a National Scheme
2. We support the inclusion of all persons with a long term physical, cognitive, mental or sensory disability that impairs their ability to fully and effectively participate should be covered by the scheme.
3. This would reflect the range of persons eligible from those with severe and profound disabilities whose needs may be more evident, through to those persons with mild to moderate disabilities who, with access to appropriate services, may fully reach their potential to participate and contribute in life.
4. The scheme should be no fault.

## 4. Who Gets the Power

1. Power should be underpinned by the key principle that all people with a disability have the right to the same quality of life as their peers
2. The power is to be placed clearly with the person with the disability or their family or their carer.
3. In Early Intervention, a qualified support professional would be allocated to assist, support and advocate for families with babies and children with special needs, to assist families to be empowered and make informed choices through navigating the disability schemes and services
4. Post Early Intervention, a family may chose to employ or access a qualified support professional to facilitate their access to the scheme and services

## 5. What Services Are Needed and How Should They Be Delivered

For our target group the minimum services that are needed are:
1. No wait lists
2. Early access (from point of diagnosis) to family support including counselling, respite services, integration support with child care and kinder, parent support groups,
3. Early access to paediatric, post graduate experienced clinicians (from point of diagnosis) for high quality, regular therapy that address functional daily skills, provide measurable written goals and outcomes per treatment block, which is family centred and partners with each child's family or carers.
4. Early monitoring for high risk babies (0-3 months), to ensure early identification and intervention is offered at the optimal time
5. Adequate support for a child within the education setting chosen by the family for their child including adequate therapy, integration aids, specialised equipment, training for staff and individualised education programs as required

6. Timely provision (within 6 weeks of prescribing equipment) to aids and equipment
7. Choice of centre based service and/or home based, and/or childcare/kinder/school services.
8. Investment in specialised training to provide adequately training clinicians to facilitate no wait lists.
9. Recognising the need for persons in rural and remote areas - additional resources are required to provide adequate service.

6. Funding Options

    1. We agree with the proposal that the NDIS should be funded by a tax funded scheme similar to Medicare.
    2. This would move funding for disability services welfare based model (based on what services are available) to a “meet the need” based scheme for any person, over the person’s life time needs.

7. Organising and Implementing Disability Policy

    1. The scheme should be nationally administered and coordinated to delete regional discrepancies
    2. It is essential to ensure continuity of care across all ages
    3. Highly recommend NDIS is supported by a national central information management system of services and resources
    4. Investment in training, career planning to support the sector long term
    5. Effective , efficient and equitable NDIS with ability to respond flexibly changing needs
    6. Consumer driven

Attachment: Early Childhood: A Vision for Victoria
Reference: www.kidsplus.org.au

# EARLY CHILDHOOD INTERVENTION:

# *A VISION FOR VICTORIA*

## *A contribution to public discussion & the strengthening of early childhood intervention services in Victoria*

The Victorian Women's Trust, Gateways Support Services & Kids Plus Foundation
*August 2008*

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# Introduction

ECIS has a history of skilled, committed multidisciplinary professionals who are passionate about best outcomes for children with disabilities and their families.

Over recent years there has been a growing evidence base about the importance of early intervention.

However, the early childhood service system is under extreme pressure and is at risk.  The unit cost structure is a historical average and does not in any way reflect the actual needs of children with disabilities and families.

We have growing demand and long waiting lists. This means that distressed families can not access the services they need to give their children the best start in life, creating severe stress and disillusionment for people at a critical stage in dealing with the grief of discovering their child has a disability.

Attracting and retaining staff for this sector is becoming increasingly difficult due to the complex nature of the work, large workloads, and better career and pay opportunities elsewhere. Staff burn out is a serious issue.

In partnership, The Victorian Women's Trust, Gateways Support Services and Kids Plus Foundation invited professionals and parents to share their professional and personal knowledge and experience, at this critical time, to develop an inspiring Vision that provides for essential services and supports for young children with disabilities and their families.

This is the result….

# Our Vision…

**Imagine…** **It is 2013 and wherever you go in Victoria you see all the signs of a State that knows how to deliver quality early childhood intervention services. Victorians embrace the principle that all children with a disability have the right to the same quality of life as their peers.**

**Check around and you find there are no waiting lists to access early intervention services such as family services coordination, a full range of therapy, inclusion support, parent support, and flexible funding. Children and their families never have to wait to get vital pieces of aids and equipment, such as communication devices or walkers. It is all there as soon as the need arises.**

**Early diagnosis and good communication seems to be the unwritten rule. Go to any of the medical training schools and early childhood intervention training programs and you hear emerging professionals being urged to listen to and heed the early feedback from parents, to do whatever they can to bring about developmental assessments and to work closely with related professionals in order to maximise knowledge and support for families. These people all understand that parents are embarking on a totally unexpected journey and that they need support. Initially, support counselling is offered to parents as a matter of course. The needs of siblings are also acknowledged.**

**Services out on the ground are exceptional – across *all* metro and country regions. There are no regional disparities. These are flexible, tailored and responsive to the needs of individual children and families, relevant and regionally co-ordinated. They cover the full range of disabilities, including physical, developmental, cognitive and behavioural disabilities. Each child is valued and recognised as having individual special needs and hence funding and access to resources is tailored to each child in a time critical way. There is good access to a range of organisations and programs which specialise to meet specific needs of specific disabilities and these are acknowledged for their high level of expertise and the corresponding outcomes for children and families.**

**It is obvious too that the early childhood intervention sector is valued. There is a workforce strategy in place not just making sure that wage structures are fair and adequate to attract and retain experienced staff but also ensuring that the longer term workforce needs such as career paths and professional development are being provided for.**

**Going from agency to agency, you see early childhood intervention professionals working well across agencies, linking families to services and supports. Their funding enables them to provide staff and resources for regular outreach service that overcomes the social and geographic isolation of many of the parents. The links between hospitals and community-based services are direct and effective. Specialists and other staff know who to contact for effective service responses. There is strong support and encouragement of research that helps, among other things, to identify further improvements in service quality and effectiveness.**

**Constant form filling non stop applications and meetings for different resources, programs, benefits, kinder inclusion and funding have disappeared – a fully**

**integrated one stop system provides a seamless administration assisting families and professionals to access what is needed when it is needed for each child.**

**The information services for parents and families are first class too. Reflecting an understanding that parents should not have to search for information vital to coping and managing their child's disability, information services are well-co-ordinated, seamless and effective. Families have access to clear, accurate information and are able to make informed decisions. There are resources too, often in the form of group facilitation, spaces and equipment, for parents to come together so they can draw on each others' experience, enjoy some positive peer support and have playgroups for their children.**

**Keen to extend the practice of social justice and social inclusion, Federal and State Government and the wider community have embraced the principle that families raising a child with special needs have enough on their plate without having to beg and plead or fundraise to purchase aids and equipment. A special social insurance scheme funded by a small levy on all taxpayers is now in place, taking the worry away from these families and allowing them to concentrate on the needs of all their family members. Families that had to make huge outlays, such as $15,000 for a motorised wheelchair, could do so straightaway without incurring onerous family debt. A range of respite support for parents is readily available to take away some of the stress and to enhance parental capacity to care for their whole family.**

**A broader striking feature of the Victorian scene is that there is a genuine cultural commitment to a whole-of-life principle in preparing the life journey from infancy. Apart from intervening as early as possible, there is the best possible professional support to ensure that people with disabilities are able to engage and participate meaningfully as members of their society. Children's access to education is highly regarded and support for child care and kinder is based on providing the best educational possibilities for each child, not merely on them being included in the room and attending safely.**

**Properly funded, early childhood intervention services are able to attract and keep staff and are well-placed to provide the best family-centred practice. You see teams of professionals – paediatric physiotherapists, occupational therapists, speech pathologists, dieticians, psychologists, paediatricians, early childhood teachers, family service coordinators and other specialists – all coming together as players in the child's life, empowering families and further strengthening family capacity for the tasks ahead. Teams work together to meet each child's developmental, functional and clinical needs.**

# 1 Two Early Childhood Intervention Roundtables

have enabled us to come to this Vision….

A Vision like this has a simple starting point – Every child has the right to a quality of life.

Several months ago, an exploratory conversation took place between the Victorian Women's Trust, Gateways Support Services and Kids Plus Foundation. The agenda was simple. What needed to be done to lift the bar and improve conditions for families and children who needed early childhood intervention services?

The Victorian Women's Trust needed no convincing as to whether it could try to assist. Much of the primary care load is carried by women throughout the broader community. Improve the conditions of care for women, and everyone benefits.

We felt it was important that a positive vision was articulated regarding the interventions and supports of children with disabilities. We thought it was equally important that this vision was crafted after listening to the views of those who had direct experience – as parents and service providers. Tasks were divided. Kids Plus Foundation and Gateways would bring the two groups of participants into the Roundtable discussions. The Victorian Women's Trust would facilitate the discussions, meet the costs of the transcription service and draft a vision statement that enjoyed the confidence of all participants.

We held two Roundtable discussions on Thursday 31 July, 2008, at the National Disabilities Services offices in Melbourne.

# 2 Parent Participation

Ten parents and one adult daughter with a disability attended the Parent Roundtable.

They came from various locations – East Doncaster, Mount Waverly, Geelong, Montrose, Lilydale, Brunswick, Macleod and Northcote. They included:

- A mother whose 20 year old son was born 8 weeks premature and has cerebral palsy.
- A mother with 2 sons. The oldest is 12 years old and was diagnosed with autism at 2 years.
- A mother with 4 children. One of these is a surviving identical twin, a daughter who was diagnosed with severe cerebral palsy at approximately 6 months of age.
- A mother whose fourth child, now 6 years old, was diagnosed soon after birth with severe cerebral palsy.
- A mother with 3 children aged from 3 to 8 years. Her middle child is 6 years old and was diagnosed at 2 years of age with severe autism.
- Parents whose 7 year old son was diagnosed at 9 months with Angelman's Syndrome.
- A father with 3 children. His twin girls were born at 33 weeks and are now 5 years of age. One twin was diagnosed at 15 months with severe cerebral palsy.
- A mother of 2, she was accompanied by her 20 year old daughter who had transverse myelitis when she was 19 months old and became quadriplegic.
- A mother with an 11 year old son who was born at 26 weeks and diagnosed with cerebral palsy at approximately 12 months.

# 3 Professional Participation

Fifteen practitioners attended the Professional Roundtable. These included:

- A former teacher and music therapist who has now worked in parent support within early intervention for six years.
- An occupational therapist with 31 years of experience in early intervention, particularly in providing services for children with cerebral palsy.
- An occupational therapist for 40 years who had worked in the autism area for last 16 years.
- A professional involved with early childhood intervention for 15 years including autism research and project manager of autism consultation and training strategies.
- A community worker in early childhood intervention services for almost 20 years.
- An occupational therapist with 20 years experience, including service provision in country Victoria.
- An occupational therapist with 20 years experience, managing early childhood intervention for the past 7 years.
- A researcher, lecturer and practicing psychologist, and Director of an early childhood intervention program
- A CEO of an early childhood intervention and inclusion support program.
- A clinician, clinical adviser and researcher specialising in mental health needs of individuals with more complex disabilities.
- A hospital based physiotherapist, clinician and researcher with a PhD looking at early intervention programs for premature infants.
- A hospital based physiotherapist working in developmental medicine and neonatal intensive care.
- A speech pathologist for 30 years, with the last 23 years working in the disability area, 13 years' experience working with children with developmental delay and 10 years experience managing services for children with autism
- A paediatrician who heads the Developmental Medicine Department at the Royal Children's Hospital
- A paediatric physiotherapist working in disability services for approximately 6 years.

# 4 The Voices of Parents

We basically didn't get more than a couple of hours' sleep at a time throughout the night for the first two and a half years of her life…

We just want him to have the best quality of life, best possible life he can have and we love him no matter what…

By day 4 the nurse said to me, "Look, you haven't even had a hold yet, you can't even put your hand in to touch him." So she pulled him out, she said, "I've got everything ready," and she gave us a cuddle and he stopped fitting from that moment on. He turned - he heard my voice and he turned and he just looked at us and he just had this knowing look in his eyes of, "It's okay." Day 5 they did an MRI scan and found that he had severe brain damage to the basal ganglia area of the brain which is severe cerebral palsy, so we were told at day 5 and they said to us pretty much that, "Your son will never walk, talk, he'll never do anything." So we were sent home with a child that they said pretty much, "Go home and just wait, he probably won't be with you for long." He's still here today and he has very high medical needs … I think we'll have him for quite some time. He has defeated all the odds of what they first told us…

From six weeks I was saying "I'm concerned about our son. This is very difficult to live with"…and (the paediatrician) just thought I was an overwrought, over anxious mother and suggested it was colic and reflux and prescribed some medication which did nothing. So that continued for eight months. He screamed in the car, he screamed in the pram, I couldn't go shopping, it was very difficult and challenging…

By the time they figured out that there was something wrong with my spinal chord it was too late to do anything…I was in hospital for fifteen months because I had a lot of breathing issues and stuff…basically I lost all my muscles, and then eventually I went home and here I am….

When I held our son as a baby, he would go very stiff in my arms and throw his head back and when he was three months old, we saw a paediatrician about that because we were concerned that he was having epileptic seizures, because I have epilepsy myself and years later the paediatrician revealed to me that he had made a note on our son's file saying "Question, autism" when he was three months of age, but nobody ever said anything to us about it….

I know from a doctor's perspective they follow the scientific route…cutting out all the obvious things first and then look at probably the less likely. But I think the focus has got to be on, 'listen to what the parents are saying,' and use that as the starting point….

It took two years to fully control his seizures, so if that had been recognised earlier and controlled better, how much better would he have developed during that time? The sleep issues we went through, the sleep clinic, he was on melatonin and Vallergan. We both lost our jobs because neither of us could continue to work….

The key to early intervention is early diagnosis…I just think they should re-write Diagnosis 101 to include the step "Ask the mum."…

The individual staff and the organisation made a huge difference…there was a special needs playgroup where parents got together, where their children were given therapy as part of play or play as part of therapy or whatever and we met other parents and talked with them. That was really good….

The co-ordinator at our son's child care centre…was instrumental in organising meetings with the physio, occupational therapist and all the other specialists, getting the staff on board. We'd have group meetings and we'd all be working together on what was best for our son….

My daughter attends two different services. They talk really well and that makes such a critical difference for that on-going care…I really like the family-centred approach, empowering the parents to actually make judgements and get active in actually providing it there….

The paediatrician said, "Do you know what? We're going to throw away the textbook, watch (your son) and let him tell his story." One time in hospital, he said (to our son) "Have you something to say?" Our son got a communication book out and said yes with his head. He's been taught how to nod, yes or no, and he told the doctor to get down on the floor and roll, and the doctor did, in front of six students, and that was the difference between a doctor who was willing to listen to our son, to a doctor that would normally just look over and talk over him, so he made a huge difference…..

The Cerebral Palsy Education Centre opened up our world…in the other early intervention, he was using two cards, making choices, and if he didn't want those choices, he would turn his head away. We got to CPEC and within ten minutes they had him fully communicating with us, saying that he wanted to play with bubbles, that he wanted to go outside and he was able to tell us….

Parent support has been and continues to be really significant and incredibly important in our life…there's a connection with families with other children with special needs…there's that empathy and understanding, that sharing of common experiences which is so helpful….

What if our son had started early intervention at six months of age rather than two years of age, how much better would he be?....

She's going to need a new wheelchair, a new toilet chair, she's going to need a motorised wheelchair…a communication device that cost $15,000 lasted for four years and I need another that costs $12,000…We got $17,000 towards a hoist to put in the $55,000 car that we took a huge loan for because we needed a bigger car with the three other children…..

It took eighteen months to get our first communication device…we are talking about a child being able to talk to us….we got (the money) from about four or five different charities and we had to write letters and …go to dinners and talk to people…I'm not saying I minded doing so, but it's an enormous amount of effort and energy into getting some funding for something that she should have had from day one…..

We couldn't access case management; there was no overnight out-of-home respite facility for kids under five. Had there been, where he could have gone one night a week, where we could have just recouped some sleep…you know, we could have maybe maintained a job…..

So you're hit with this life-changing diagnosis and then just sort of placed on a waiting list until the early intervention service has a spot, so I think that's an incredibly difficult time for families when there isn't much support available…..

My daughter had acquired her disability as an accident of pregnancy. If she had been born perfectly normal and then, on the drive home from the hospital, there was a car accident, she would be covered…..

# 5 The Voices of Professionals

Every child has a right to the same quality of life, the same expectations, the same abilities as their peers…and whatever that cost in terms of people, resources, money, whatever, that should be available…..

I never cease to feel the impact of making a diagnosis on a child of severe cerebral palsy or Down's syndrome or many different things. The impact is huge…..

Once having made the diagnosis…I have families in tears, there's really not a lot of help with their immediate grief….One has to send them away and there's huge grief and huge disappointment and failed expectations, all of that…..

We'd like to offer the full range of things (but) from a resource point of view, we just can't…..

We need to recognise the family's strengths and skills and styles and priorities. The way a family works has to dictate the way that we, as workers, work…..

We've started off being child focused and we've extended to saying that we need to work with families to be more effective. We're now saying that we need to be broader than that and working in everyday settings to be effective. All of these are justified in terms of what is necessary for child development, but we don't have the resources, the research or the professional development to support that process…..

If only we had a timely, quality service…not a second-rate service, not a waiting list or a band-aid service, but a service that actually helps you and your family to reach your potential and be valued members of our community…..

If only families could enjoy good quality of life, where they know they've actually got choices and they're satisfied with the service they're getting for their child, and they can meet the needs of other family members, so that, in terms of a life worth living and a future to look forward to, that –on a daily basis – they're not torn because they are just dealing with the grief issues and accepting their child…..

If we as a community were really committed to all adults with disabilities being really engaged in the community….then we would need to rethink how we were preparing the life journey from infancy. That would mean we would be saying we need to intervene as early as possible…we need the best professional support to create that career path, as it were, to being meaningful participants…..

The provision of appropriate services, whether it is psychology, OT, physio, simple respite, the ability for parents to get a break, a lot of these things are essential and families said they could not survive without them and I think that is something that is very fragmented here for many families…..

We see huge disparities between country patients and our Melbourne-based patients, but even within Melbourne, the disparity between east and western suburbs is huge….Some of our patients wait for up to two years for an early intervention placement, particularly if they live in the west…..

# 6 Realising this Vision

This Vision is achievable. But it will require, at least, the following:

- ✓ A shared *commitment at all levels* to an ethos that acknowledges the basic rights of every child to a quality of life which fundamentally includes; safety and protection; the support and resources needed to help their individual potential for communication, mobility and self care; access to education; inclusion, participation and the opportunity for contribution; and ultimately to live as independently as possible

- ✓ The comprehensive understanding that within the full spectrum of disabilities *there is a correspondingly huge range of individual developmental, functional and clinical needs:* and the current generic standardised funding of places or “targets” does not meet the needs of many of these babies and children. These children require individualised funding to meet individual needs at any given time.

- ✓ A Workplace Strategy that ensures there is a *valued, sustainable and professional workforce that can deliver quality, specialist early childhood intervention services.*

- ✓ A funding scheme for aids and equipment that removes the financial burden and stress from families by *meeting the immediate and full cost of items, with no delays.*

- ✓ A break with the mindset that the current level of funding and service provision is sufficient.

  *A significant injection of Federal and State funds is required immediately and permanently to ensure a sustainable ECIS in Victoria that has no waiting lists for children at a most critical time of their lives, and actually meets the needs of each and every one of these children and their families.*

# 7 Parent Participants

**Liz Manning, Bronwyn Evans and her daughter Jess Kapuscinski-Evans, Meredith Ward, Diane McCarthy, Donna Henderson, John Innocenzi, Lisa Kohinga, Maurita Carlisle, Penny and Matthew Potocnik** participated in the RoundTable. Some of these parents would also like to share their stories.

## Donna Henderson

*Prior to the birth of her 11 year-old son Patrick, Donna worked as a General Practitioner in the Eastern suburbs of Melbourne. Patrick's premature birth and subsequent diagnosis of cerebral palsy at 12 months forced Donna to grapple with the fragmented and uncoordinated system she had previously referred patients to, often with far less resources than she had.*

*Donna became very active in advocating for not only her family but for other families as well, serving as a member of several disability-related committees. Donna now works at the Association for Children with a Disability, where she is involved in community education of health professionals in developmental disability as well as advocacy around the health issues for people with disabilities.*

*Donna is only able to work part-time, however, due to the high requirements of Patrick's care. Patrick has severe physical disabilities, is unable to sit or stand independently and requires full assistance for all activities of personal care and recreation. Every day Patrick requires at least 4 hours of direct hands–on personal and positional care. Patrick is however, fully verbal, socially astute, mobilises in a manual wheelchair and has above average intelligence. This mismatch between physical and cognitive ability has meant that Patrick intellectually is best suited to mainstream services but considerable input is required from many people to meet his physical needs in these settings.*

## Liz Manning

*We had 5 babies but 4 surviving children (one twin was still born) with ages ranging between nearly 4 1/2 and 14 years. Penny is the second oldest - she is 11. She has severe cerebral palsy and needs assistance with toileting, feeding, transfers, communication, seating - the whole bit.*

*Equipment needs are EXTREMELY expensive, and she never gets equipment in a timely fashion. Penny has had multiple operations and is developing scoliosis. BUT she understands everything we say, she has a wicked sense of humour, loves school, reading, dolls and being with her friends. She is patient and long suffering. She adores her younger brother and tolerates her older brothers, and loves it when they play with her. Penny tells us off if we annoy her and shakes with laughter if we do something silly. She can be very cheeky! People who meet her and get to know her tend to adore her. Many people have found more meaning in their own lives because of Penny. She is very much her own person and has her own zest for life.*

*We both work full time and never have enough time for home or work, particularly recently after a major operation. We manage by not getting enough sleep, and by crisis. We want to do enough for our other children as well, but inevitably they miss out. This makes me very sad. Fighting for funding or Penny's rights/needs is exhausting and saps our limited energy, taking away time from Penny and the other kids. Wrestle with the problem of sacrificing other kids for Penny or vice versa, but are stuck with doing the best we can. Most of the time this does not feel like enough.*

*Our health/fitness/weight levels suffer. We often use recreation leave for caring, and we need a holiday after recent traumas.*

*Accessing after-school-care and holiday-care is a continuing problem for people who work and only get 4 weeks a year leave, as most programs cannot cope with Penny. We rely on a mishmash of solutions to survive…*

## Bronwyn Evans & her daughter Jess Kapuscinski-Evans

*Jess, now 20, became quadriplegic at the age of 19 months after developing transverse myelitis. She has no use of her hands and cannot sit up unless fully supported, but drives a motorised wheelchair using head controls. Jess had early intervention at her doorstep for 15 months, as respiratory problems kept her an inpatient at the Royal Children's Hospital until she was nearly 3 years old. Jess benefited greatly from regular sessions with physiotherapists, occupational and speech therapists. These sessions were fun, provided Jess with motivation to try new things, and allowed us all to explore options for wheelchairs, tilt tables, and other equipment. Initially at home Jess had no formal intervention, but her Nan and a wonderful RDNS nurse provided Jess with lots of activities.*

*During 1992 and 1993 Jess attended both the Yooralla Early Childhood Service in Glenroy and a local mainstream kindergarten. Yooralla staff helped Jess to explore her physical capabilities, for example setting up a sling and a splint for holding a pencil so that she could use shoulder movements for drawing. The occupational therapists also introduced Jess to using a switch that she could hit with her elbow. During primary school she used this setup to drive scanning software for a computer and to operate a page turner for reading. The local kindergarten, on the other hand, was very important in setting up the collaboration between carers, teachers and ourselves that provided a model for Jess' school years.*

*Jess attended mainstream schools, and is now doing a Bachelor of Arts degree at the University of Melbourne as well as extra-curricular activities, including membership of the Youth Disability Advocacy Service steering committee.*

## Diane McCarthy

*For the past 10 years of my professional life as a parent support worker at the Association for Children with a Disability I have worked supporting other parents of children with a disability with the issues that they are facing. I am able to draw on my personal experience as a parent of a young man who has a caring nature, a wicked sense of humour, enjoys socialising and going to concerts and whose spirituality is a key focus in his life.*

*When I look back at his infant and pre-school years I wonder how we have come so far. I recall his early delivery and anxious times in hospital, our concerns as parents that his development was not the same as his brother who was born 14 months earlier. Also the difficult times in trying to indentify who could help us identify what was "wrong with him" and who could help him "catch up to his brother". I recall the stunningly painful times when we finally received the diagnosis of cerebral palsy - severe spastic quadriplegia and that at that time the paediatrician almost congratulating me for having actually found services before the diagnosis.*

*It always seemed to be us finding out what services were available, how to access them, how to ensure the right mix of qualified professionals saw and treated our son and who educated us on how to maximise every facet of every attempt Brendan made to be an active participant in his life. We have worked hard over the years to support our son to be the person he is today but neither he nor we could have travelled this road without the dedicated, professional team of early intervention workers who ensured that we had the skills to continually challenge him to strive further.*

*As a parent I had always thought my journey was unique no one else could possibly have travelled down this same path. As a friend I have often heard similar stories of others I have known over the years. As a parent support worker I am always saddened to hear the same story, a mirror image of my story, repeated every year. Mothers instinctively knowing something is not right with their child's development, going to medical professionals, not being heard, seeking assistance for their child and finally receiving a diagnosis only to walk out the door of the surgery without any understanding of the next step and where to get assistance for their child.*

*Family's stories should be different 22 years on. Families should be able to have immediate access to high quality services that assist their children and build their resilience as parents to continue to strive for the same sort of lives as other children.*

## Maurita Carlisle

*Michael and I have three beautiful children aged 8 years, 6 years, and 3 ½ years. Tom is our middle child and was diagnosed with classic autism at the age of two years.*

*From very early infancy, Tom was an extremely unsettled and distressed baby. He would wake anywhere from 10 to 15 times per night, and would scream most of the day and night without being able to be comforted. He would scream at home, in the car, in the pram, out at the shops and would only ever settle if he was held upright and facing outward. Tom's paediatrician was unsympathetic (making me feel like an overwrought and overanxious mother) and diagnosed colic and reflux, prescribing Zantac medication for treatment. The medication was completely ineffective and with no further medical follow up, I felt completely alone, depressed, desperate, exhausted and without any meaningful help.*

*When Tom was about 8 months of age, his screaming began to settle to some extent as he began to sit upright and started crawling, and I recall vividly that for the first time I felt I was able to hold and comfort my baby and enjoy being with him.*

*Tom began walking quite early at around 11 months and by 12 months he was running, and he really hasn't stopped running ever since! However our concerns about Tom's behaviour and development continued throughout this time, as he was still a very unsettled and challenging baby and toddler and displayed many difficult behaviours including hyperactivity; lengthy tantrumming and screaming over the slightest frustration; limited play skills and concentration; and a significant speech delay.*

*When Tom was 18 months of age, I raised my concerns about Tom's development with my local Maternal Child Health Nurse. I was advised by my MCH nurse to continue to monitor Tom's progress and that she would conduct a further assessment of Tom at the two year old check up. When Tom turned two years of age, I returned to the MCHN, again expressing concerns about my son's development and behaviour, and she suggested that Tom undergo a full developmental assessment. I subsequently made an appointment with my family GP that same week, requesting a referral to a paediatrician for a developmental assessment. The GP unfortunately was also quite dismissive of my concerns, laughing and saying "there's nothing wrong with him, "look…he has good eye contact, he is looking at me", but nevertheless he agreed to a paediatric referral at my insistence.*

*Later that same week, I made an appointment for Tom with our local paediatrician to have a full medical and developmental assessment. After a fairly brief preliminary assessment, the paediatrician said very frankly and quite bluntly that he believed that Tom had "Autism" and that he would refer him for further speech and psychological assessments to confirm the diagnosis. I was completely shattered and walked back to the car in a total state of shock and disbelief, not being able to comprehend what I had just been told. I knew nothing about Autism, other than what I had seen on the movie "Rainman" many years before, and my beautiful boy seemed nothing like that.*

*Following this first visit, the complete assessment of Tom took approximately three months (and about 15 assessment visits in total!) and in April/ May of that year Tom had a confirmed diagnosis of Autism in the moderate to severe range of Classic Autism with an accompanying intellectual disability.*

*The impact of Tom's initial diagnosis was quite profound and life changing for both Michael and myself. It was recommended by the paediatrician that we seek early intervention for him as soon as possible, to begin to address his speech, sensory and other developmental issues. We were given a list of several different early intervention services to contact and placed Tom's name on all of their waiting lists.*

*Sitting on a waiting list for early intervention was one of the most desperate and difficult times for us. Dealing with intense feelings of shock, denial, anger and grief; and with very limited knowledge and understanding of autism; this was the time when we really needed as much support, education and assistance as possible and yet nothing was immediately available. A place became available for Tom at Irabina Early Childhood Intervention Services approximately six months later; however the waiting period for early intervention can be much longer around the state.*

*Tom attended Irabina for a period of almost four years and received both individual and group based therapy from a multidisciplinary team of qualified and highly skilled professionals, including psychologists, speech therapists, occupational therapists and qualified teaching staff. We are so very grateful to the amazing staff at Irabina for their wonderful support and understanding; for the training and education we received as Tom's parents; and for the behavioural and developmental intervention that Tom received over the years. We learned such a great deal about Autism throughout our time there and the many and varied ways in which we could support and care for our beautiful son. Tom has also developed some very special relationships with several of his therapists at Irabina over the years and* *these wonderful therapists have continued to remain involved in Tom's life as he has embarked on the next stage of his journey and made the transition to primary school.*

*This is a very difficult and challenging road that we travel as parents of a child with autism, and requires very flexible and extraordinary parenting at times, it is not only possible and manageable, but can be incredibly fulfilling and rewarding with the right kind and level of help and support.*

## Penny & Matthew Potocnik

*Levi is 7 years old and was diagnosed with Angelman's Syndrome at 9 months. He is an extremely social and happy child who loves the company of other kids, water, music and watermelon. Levi communicates by 'looking' at objects, moving his head, vocalising and choosing between cards depicting objects. He uses a wheelchair to get around but can weight bear and will walk (sometimes) with assistance and with a walker. Levi is a 'sensory seeker' and is motivated to explore different textures, particularly with his mouth. Levi needs lots of sensory input through deep massage for him to focus on tasks, such as walking & communicating.*

*Levi is an only child who lives at home with Mum & Dad in Brunswick. Levi attends Glenroy Specialist School 5 days a week. He travels on a bus for nearly 4 hours a day to attend school, (but that's just another story!)*

*Levi first sat up aged 3. Levi does not sleep very well; aged between 2 and 4 Levi woke every 2 hours throughout the night often screaming. Only a bath would stop his screaming; Levi was in real and unrelenting pain. Levi had the onset of seizures (aged 2) and also has severe constipation (for both he has had hospital stays). Levi is on daily medication to control his seizures and also takes medication and a follows a 'regime' to maintain bowel health. Levi also has life-threatening food allergies (he has had an anaphylaxis to egg) and had severe eczema as a baby. An Epipen needs to accompany Levi at all times. Levi needs assistance with all aspects of daily life; ie. Dressing, eating, bathing, playing.*

*As parents, our lives have changed focus enormously. At one particularly 'low' stage (that lasted at least 6 months), we needed attendant carers to come to our house to help us get Levi up, dressed and fed; and because we were so sleep deprived we required someone to drive Levi to creche, as it would not have been safe for us to do so. Our lives are now structured so that we both work part-time, one during week days the other on weekends, so that we can both maintain our work and Levi's care needs.*

*Our saving grace in the early years was Levi attending crèche. Levi was well supported by staff and therapists from Specialist Children's Services. The cost was about $9,000 a year; but was absolutely vital for Levi and our family to maintain a 'quality of life'.*

*Now that Levi attends school we have become better connected to supports; we are lucky in that Levi qualifies for a Support & Choice Package. This has allowed us the dignity of not needing to approach charities for top-up-funding for essential equipment; and has given me an extra pair of hands when I take Levi swimming on Saturdays.*

*The constant need to advocate for Levi's needs is an ongoing challenge for us as parents. Thanks for listening to our story and for creating this Vision. I look forward to the day this Vision is truly embraced; it will be a great step up for humanity..*

*Penny Potocnik*

*Levi's Mum*

# 8 Professional Participants

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| Dianne Bailey-Tribe | CEO | Irabina Childhood Autism Services |

*Dianne Bailey-Tribe trained and became a leader in her fields of Occupational Therapy, Psychotherapy and Community Services and has worked with children and adolescents with mental health issues for 27 years. Her qualifications include Bachelor of Applied Science (Occupational Therapy), and Child and Adolescent Psychotherapist Post Graduate Program.*

*Dianne has been the Executive Director of Irabina Childhood Autism Services since 1999 and has guided the delivery of Irabina services to be family-centred, evidence-based and individualised to the needs of every family. Irabina provides autism-specific early intervention programs for young children and their families living in the eastern metropolitan region of Melbourne.*

*Dianne is a Trustee of Occupational Therapy Research Trust Fund and in 2007 was elected to The Victorian Honour Roll of Women for her contribution to the field of Autism.*

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| Sue Bray | Manager, Early Childhood Intervention Services | Yooralla |

*Sue Bray has been manager of Yooralla's early childhood services for the past 7 years, overseeing 10 ECI services which provide services to over 400 children with disability, 3 of which are also Kindergartens providing best-practice inclusion programs for 3 & 4 year old children with disability alongside their same-age peers. Sue has also managed Kindergarten Inclusion Support Services and ECIS Flexible Support packages in southern metro Melbourne.*

*Sue has 15 years experience as a community paediatric Occupational Therapist and Clinical Advisor. Sue completed her Masters in International Public Health in 2006 and has, on four occasions, been seconded by Charles Sturt University, Albury, to supervise Occupational Therapy, Physiotherapy and Speech Pathology students on clinical placement at an orphanage for children with disability in Vietnam.*

*She is current Vice-President of ECIA (VC) and is involved in a number of advisory groups related to the field.*

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| Kerry Bull M.Spec Ed. | Special Educator, Early Childhood | Autism Consultation & Training (ACT) Now, Monash University |

*Kerry Bull is currently the Project Manager of the Autism Consultation and Training – NOW Strategy (ACT-NOW) at Monash University, Centre for Developmental Psychiatry & Psychology. She co-ordinates Regional Autism Coordination Teams across Victoria and provides autism consultation and training to the early childhood and early intervention sectors. She also works in private practice as part of a multi-disciplinary team providing assessment, individual child therapy, parent education and skills training programs, professional consultation and professional education and training programmes.*

*Kerry has worked extensively in the field of early childhood and special education as a teacher and manager of early childhood intervention programmes in Melbourne and rural Victoria. She has also worked in the Monash Autism Early Intervention research project 'Pre-schoolers with Autism: An education and skills training programme for parents'.*

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| **Claire Cotter** | **Centre Manager,<br>Occupational Therapist** | **Cerebral Palsy Education Centre (CPEC)** |

*Claire Cotter is an occupational therapist by training. She has an Honorary Diploma in Conductive Education from the Andras Peto Institute for Conductive Education in Budapest, Hungary and has studied at this Institute for six months, as well as trained at the Bobath Centre in London and completed two Bobath refresher courses. Claire has spent some time studying sensory processing disorders and technology access for children with severe cerebral palsy and complex communication needs., and has worked in the field of children with cerebral palsy (and like disabilities) for 31 years. She has co-authored a book and contributed to published resources on cerebral palsy and conductive education for the Queensland Department of Education.*

*She has been a member of trans-disciplinary teams of therapists and teachers for over 20 years and works alongside Gayle Porter who is the internationally recognized expert in alternative and augmentative communication for young children with complex communication needs (CNN). Claire supports and seeks funding for Gayle work. Gayle's PODD (Pragmatic Organizational Dynamic Display) communication book resource has already been translated into three other languages and the USA version is being released this month. Gayle's resource is the future in communication for people with complex communication needs – and the ability to communicate is the fundamental right of every person. Claire and her team provide professional training at a range of levels: undergraduate OT's, therapists, teachers, kinder and daycare support staff, parents, and leadership teams in mainstream schools.*

*Claire is the Manager and Senior Occupational Therapist of the Cerebral Palsy Education Centre in Glen Waverley, Victoria – a Centre committed to best practice and outcomes for children with severe physical disabilities and complex communication needs and their families. Claire and her colleagues are absolutely passionate about quality outcomes for young people with severe disabilities and their families. She works with families on a day in/day out basis.*

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| **John Forster** | **CEO** | **Noah's Ark Inc.** |

*John Forster has been CEO of Noah's Ark Inc in Victoria since 2000. Noah's Ark is the largest early childhood intervention and inclusion support agency in Victoria. It supports over 1000 child care and kindergarten programs, works intensively with over 700 families who have a child with a developmental delay or disability and has commissioned a series of reports on inclusion.*

*Prior to joining Noah's Ark, John had a number of roles with the Brotherhood of St. Laurence, including Acting Director, Community Services, and worked broadly across the issues of social exclusion and disadvantage.*

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| **Julie Turner B.App.Sci. (Occupational Therapy)** | **Occupational Therapist** | **Pinarc Support Services & Kids Plus Foundation** |

*Julie Turner has worked as a paediatric OT for the past 20 years; initially with the Spastic Society of Victoria (now SCOPE) as a therapist and Senior Clinician and more recently with Pinarc Support Services. Julie is based in the Ballarat area and has a strong interest in supporting quality regional services.*

*Julie is Bobath trained (London, 1988) and has completed numerous Certificated courses in paediatrics, including Advanced Baby Certificate (NDT), Sensory Integration (SIPT Cert), Grad. Cert. Principles of Conductive Education. As well as running a private paediatric practice in Ballarat, Julie is a guest tutor with Latrobe Uni (OT School). Julie is currently providing locum services to Kids Plus Therapy Program.*

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| Associate Professor Dinah Reddihough MD BSc FRACP FAFRM | Director & Paediatrician | Department of Developmental Medicine, Royal Children's Hospital |

*Dinah Reddihough is a paediatrician involved in the clinical care of children with disabilities, particularly cerebral palsy. As part of her commitment to improve knowledge and promote best practice, she has developed a multidisciplinary research program which is focused on gaining an improved understanding of the causes and outcomes of disabilities in childhood. This program has involved physicians and allied health professionals both in the Hospital and the community.*

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| Associate Professor Susana Gavidia-Payne | Director | Education Programme for Infants and Children Inc. (EPIC) |

*Susana Gavidia-Payne has been involved for approximately 30 years in the human service and disability fields. She has extensive experience as a practicing psychologist and research expertise in the family, children's, and disability areas and in the planning, delivery and evaluation of services.*

*In her academic capacity at RMIT University, Assoc Prof Gavidia-Payne has been involved in a number of research projects related to the development and implementation of interventions and supports with families of children with a range of developmental delays and disabilities. This activity has generated publications and numerous conference presentations and reports. As a practitioner, she has been implementing support programs for families, and training professionals in the disability, family, and community sectors. Through her role as the director of EPIC, she manages a multidisciplinary team of early childhood intervention professionals who provide direct support programs for 100 children with disabilities and their families. Currently, her major focus is to work out the most effective ways to translate research evidence into good practice in the early years, so it can assist children and families and the service system that is meant to support them.*

*Finally, Dr Gavidia-Payne is the President of ECIA (VC) and is involved in several government advisory groups associated with current reforms in the Early Years government agenda.*

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| Dr Nick Hagiliassis PhD | Psychology Advisor | SCOPE (VIC) |

*Nick Hagiliassis is a psychologist with twelve years' experience in the disability field. He completed a BSc (Hons) and an MPsych at Monash University, Australia, and a PhD at La Trobe University, Australia.*

*Nick has worked at Scope since 1995, initially as a psychologist with regional Specialist Services teams, and since 2001, as the Psychology Advisor with Statewide Specialist Services. Between 2002 and 2006, Nick also worked as a senior psychologist with the Mid-West Area Mental Health Service.*

*Currently, Nick provides clinical support to a growing group of psychologists at Scope and supports the broader activities of the Statewide Specialist Services team. Nick has a particular interest in research activities that are relevant to the lives of people with disabilities.*

*Along with his co-authors, he has published and delivered a range of papers, focused on the mental health of people with disabilities. Nick is the co-author of two books with Hrepsime Gulbenkoglu, Enhancing Self-Esteem and Anger Management.*

*Nick is a founding member of the Bridging Project, a joint initiative of Scope and Centre for Developmental Disability Health Victoria, whose objective is to progress the knowledge- and services-base in relation to people with complex communication needs (CCN) and concurrent mental health needs.*

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| Rosemary Malone | CEO | Gateways Support Services |

*Rosemary Malone more than 20 years experience in both the government and NGO disability and specialist children's field and have a keen interest in responsive service delivery, innovation and evidence based practice, and inclusive approaches.*

*As the CEO of Gateways Support Services, Rosemary has a thorough and comprehensive understanding of the support needs of children and adults with disabilities, including those with complex behavioural and medical needs and their families. Gateways provides a broad, comprehensive range of responsive, flexible, individualised services including early childhood intervention, parent support, respite, recreation and supported accommodation in the Barwon region funded by both Commonwealth and State governments.*

*Rosemary is currently the Vice President of Autism Victoria, a member of the Autism State Plan Working Group, member of the DHS Regional Disability Advisory Committee, Chair of the sub regional disability NGO network, and member of the executive of the sub regional primary care forum, regional ECIS network., City of Geelong Child and Family Round Table and Surf Coast Disability Advisory Council*

*Her qualifications include a B.App.Sci. (Speech Pathology) with Distinction, Dip. Ed. and Grad Cert Man.*

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|---|---|---|
| Kelly Reynolds<br>B.App.Sci. (Physiotherapy) | Physiotherapist | Chair, Paediatric Special Interest Group, Australian Physiotherapy Assoc. |

*After completing a Bachelor of Health Science (physiotherapy) in New Zealand, in 2000, Kelly Reynolds has worked across a range of early childhood services within rural and regional Victoria. She has worked for Pinarc Support Services, in Ballarat for 6 years, providing physiotherapy within their early intervention, school-aged and adult disability services. Part of this time she was in the role of physiotherapy team leader, providing support and supervision for three other physiotherapists, as well as assisting with program development. Kelly has worked in rural areas such as Ararat, Colac and Clunes, and is now based in Geelong working with Children's Therapy Services and the Kids Plus Foundation.*

*Kelly has a strong commitment to professional development and is currently undertaking a Masters in Education, researching the ability for health professionals to transfer learning from continuing education programs. She is also in the process of becoming a Bobath tutor and has been an active member of the Australian Bobath Neuro-Developmental Association (ABNDTA). Kelly has been a member of the Australian Physiotherapy Association (APA) for 8 years, and is the current Chairperson of the Victorian Paediatric Special Interest Group.*

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| Bronwyn Lawson<br>B. Music Hons (Therapy), B. Education | Parent Support | Kids Plus Foundation |

*Bron Lawson is currently working as the Parent Support Worker at the Kids Plus Foundation, Geelong, and provides direct parent support to families who are new to the service, require support in working with other service providers or are in a crisis. She also provides general information and support to families by providing brochures, newsletters and information about services and running information workshops specifically aimed at families who have a child with a physical disability.*

*Previously, Bronwyn worked at Noah's Ark, Geelong, during a time when the service moved from providing a resource library and parent support playgroups to providing a complete EI service for families based on a key worker model. During her primary school teaching career, she also coordinated the inclusion program in a country primary school.*

Penny Ryan
**Early Intervention Worker**
**Mpower Inc., Warrnambool**

*Penny has a Degree in Occupational Therapy and has worked in Pediatrics and more specifically early intervention for 20 plus years in South West Victoria. She has extensive experience in assessment, treatment, and Family Service Coordination for children and their families in the EI system.*

*Penny is currently working at Mpower Inc. Early Intervention Team, Warrnambool, where she is involved in Multidisciplinary Autism Assessments and also coordinates ECIS Flexible Support Packages. Coordination of developmental play programs, specific skill based groups, and case management are a large part of her work. Penny has also delivered the Signposts Program to parents involved in early intervention.*

*Prior to this Penny was part of the Specialist Children's services team where she also coordinated the Kindergarten Inclusion Support Program in its infancy.*

Dr Alicia Spittle PhD
Victorian Infant Brain Study Group, Murdoch Children's Research Institute; Neonatal Unit, The Royal Women's Hospital,

*Alicia Spittle recently completed a PhD in the area of early intervention for preterm infants to improve motor outcome in the first year of life.*

*She works clinically in the neonatal unit at the Royal Women's Hospital.*

*She is also involved in paediatric education and is a lecturer and co-coordinator of paediatrics at the School of Physiotherapy, University of Melbourne.*

*In addition she is involved in research as a member of the Victoria Infant Brain Studies at the Murdoch Children's Research Institute.*

Leonie Symes
Senior Project Officer
Centre for Community Child Health

*Leonie Symes is a senior policy officer at the Centre for Community Child Health (CCCH), at the Murdoch Children's Research Institute (Royal Children's Hospital.)*
*Leonie is presently involved with the local evaluation of the national Communities for Children initiative – designed to support local community services to find local solutions to the engagement and provision of services to disadvantaged groups. Her work at the CCCH also involves presentation of Family Partnership Training and other related training, aimed to enhance the work of early years' practitioners in working with families of young children to achieve best outcomes.*

*Leonie has extensive experience in Early Childhood Intervention Services (ECIS), both as a practitioner and as a manager of a community based ECIS. In these roles, she worked directly with families of children with developmental disabilities and provided leadership and supervision to staff in this area. As an ECIS manager, she was involved in the re-development of a model of service delivery, to better meet the needs of families so as to achieve better outcomes.*

*Leonie's key interest area is 'family engagement' from a strength based perspective, and to this she brings a belief in and commitment to the process of reflective practice in early years' service delivery.*

# 9 Acknowledgements

The Victorian Women’s Trust, Kids Plus Foundation and Gateway Support Services wish to acknowledge the interest and generosity of all Roundtable participants in giving of their time, passion and experience to enable this document to come to fruition.

We would also like to thank Mr HG Fagg for his generous financial support of this project, and the staff at the National Disability Services for lending us their Boardroom for the Roundtables.

*Thank you*

*August 2008*