

# Early childhood: A time for inclusion

by Gina Wilson-Burns

"Let not our needs  
determine our dreams...  
but **let our dreams  
determine our needs.**"

Colleen F. Tomko

Macdonald Burns is six. He has severe multiple disabilities.

However the biggest disability Mac has is much of society wants to deny him an ordinary, inclusive life.

This happens physically with inaccessible venues, steps and barriers and it happens socially. Everyone everywhere wants to segregate him. For the most part it isn't malicious and most people believe they are doing the right thing - even we did in the early days. For us it started from the specialised (but 'segregated') local early intervention centre, the preconception you shouldn't attend play groups because "you might make the other Mum's uncomfortable" and the isolation you feel (and at times seek) when you have a medically fragile child. The inability to let your friends know how to help because, let's face it... you are making it up as you go along.

Your natural supports are eroded and your natural role as a mum is replaced by that of nurse, therapist, teacher and "carer".

As Mac's family we have often been told "he would be better off with his own type", "he should attend the segregated early intervention centre not a regular preschool". We were met with surprise when we sought more than five hours of private long daycare, like the other families could..., because "you need to apply to the Federal Minister for that type of irregular request".

**Thankfully a very smart little boy was able to make us challenge our own thinking and the thinking of others...**

Early childhood is the right time to set the groundwork for an inclusive life.

It is too easy to **fall into the trap of a segregated setting**,

too easy to **lose the natural authority of the family** and

too easy to **lose your way.**



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We need to invest in the child and let all children reach their potential with their peers as valued members of their community. And we need to start early!

## So how did we come to this conclusion?

My husband, Shawn, and I weren't sure if our second child would survive his birth or his infancy.

Our first child, Meg, died in surgery at just two days of age courtesy of a rare brain hemorrhage - devastating, absolutely devastating. But life, as we know, goes on.

Falling pregnant again was always going to be a nervous time, so we tried to be as positive as we could - we owed it to the little person growing in my belly to have confidence in him. Imagine our shock at finding at just 24 weeks gestation that this child was in grave danger.

Our Doctor was shattered and we were shattered. Were we really going to have to plan another funeral? How on earth could we ask people to attend another one - were we just going to bury babies?

Further tests revealed things may not be as bad as initially thought (unrelated to Meg's condition this was just another case of bad luck). Sure, our baby was in strife, but he was holding his own. He was severely growth restricted, but this meant he was "brain sparing" - he was sending all his nutrients to his vital organs at the expense of growth - smart kid, tough guy. We owed it to him to make the right decisions - he was fighting for survival and we needed to fight with him.

Mac was delivered a few weeks later. It was decided to get him out of the hostile environment of my womb and give him the best chance at survival. And survive he did. Weighing in at only 496 grams he was tiny. My wedding ring could fit right up his arm. But boy he was strong. He pulled through some tough times and, after nearly 140 days in hospital, Mac went home. He was still small and would take some time to catch up in his growth, but there were no neurological concerns, he was hitting appropriate milestones. Things were looking up - we were taking home our baby.

When Mac was six months old he caught that year's flu, I had it first, then Mac. This was far from ideal - he was very sick. On his ninth day in hospital he simply 'crashed' - it was chaos. It was a disaster. His brain was being denied the oxygen it needed and his whole body was shutting down. He was airlifted to one of the major children's hospitals. We were once again having to face the prospect of saying goodbye, forever, to yet another child.

### **Remarkably, Mac survived but it was not without significant collateral damage.**

Mac's brain had been denied oxygen for too long. He had a severe global hypoxic brain injury. His prognosis, while considered conducive with life, would mean significant disability and impairment. Mac would be profoundly disabled.

Once again our world was being turned upside down. It was only 15 months since we had consoled ourselves with the notion Meg not surviving with a severe brain injury was for the best. We had been told by many people it was for the best and, I guess, we accepted this idea.

We knew, even in Australia, people with brain injuries & profound disabilities did it tough. We had contemplated life with a brain injured child and discussed it at length.

In Australia people with disabilities are viewed by governments and, sadly, much of society, as liabilities not worthy of investment.

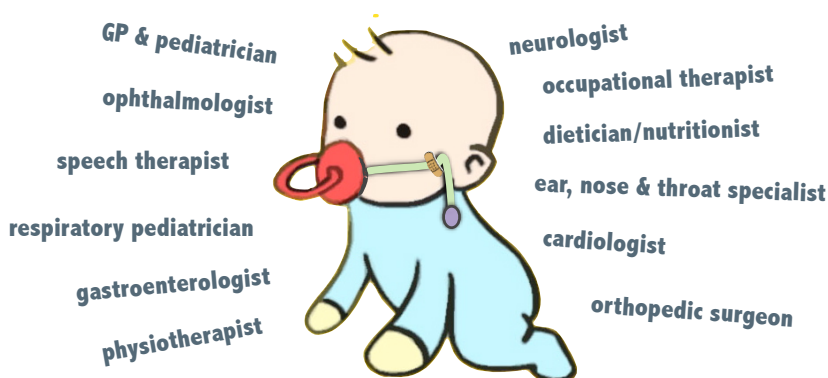
They are thought of in terms of the **'warehousing costs'** of them,

NOT as *potential contributors.*

So here we were, fighting for our child's life having removed him from one hostile environment at 26 weeks gestation into the potentially hostile environment of our society that is, for the most part, scared of disability.

The next few years centered around keeping Mac alive and trying to leave that 'acute medical phase' behind us. We were quite fortunate with our paediatric rehabilitation specialist. He advised us that his profession really had 'nothing to offer' a child as disabled as ours. His words were "all we offer is damage control and we have nothing in our armory appropriate for Mac at this time".

While it sounds 'hopeless' it was actually a good place to be. It gave us permission to look further afield, to investigate things and truly 'take control' of our child. Too often you lose control, you hand it over to the doctors and therapists and you stop making decisions for your own child.



For us it was far better to have the control. We weren't stressed or overwhelmed by the prospect and with the 20:20 vision of hindsight, we now know this was setting us up for making sound choices for Mac in future years. We travelled overseas to find therapies that made a difference, we researched, researched and researched. We questioned old ideas and we reminisced about sleep (alas, we still do).

### **But even with this 'control over our decisions' what path were we on?**

In the early days, Shawn and I, like many other parents, muddled along the expected early intervention path with a profoundly disabled child. We seemed to have either therapy or medical appointments constantly. It was incredibly easy to slip into a very 'disability centric' world.

We found ourselves cancelling social engagement after social engagement due to the 'unreliable nature' of Mac's health. We spent too many days and nights in hospitals and our ability to 'give of ourselves' outside our immediate family unit was almost impossible.

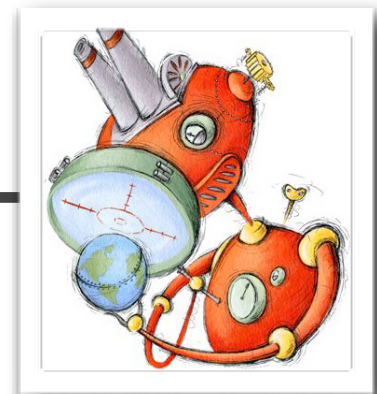
Our natural supports were slowly being eroded as we turned to those who “better understood” our situation. Parents with ‘kids like ours’. Parents who weren't phased by the 2.5m projectile vomits your child had a tendency to do (anywhere), who didn't flinch at the sight of you sticking a tube up his nose and into his stomach. Who understood every minute of your day was either feeding your child, worrying about bowel motions (or lack thereof) or trying to meet some ‘therapy objective’ because at that stage, in some instances, your child's life depended on it.

As it became more apparent that Mac was becoming less fragile and moving out of the ‘acute medical phase’ of his life we set about making some assumptions about his future.

We largely accepted that our lot in life was,

- 1) keep Mac alive, and
- 2) send him off to special school for his 13 years of education.

We didn't really think beyond that let alone consider who he would be and what he would do ‘when he grows up’.



We had made **our world smaller** and, subsequently,  
we had started to make **Mac's world tiny**.

We are very pragmatic people, we weren't in ‘denial’, we ‘got’ the severity of his brain injury and we certainly weren't ‘chasing miracles’. Quite clearly there were elements of ‘self preservation’ in this approach. We weren't prepared to think too far ahead, let alone dream big.

We had spent the first couple of years of Mac's life with his deficiencies being highlighted time and time again. You receive diagnoses of “he won't ever walk, or talk, he won't be able to feed himself, he can't see, he can't move”. You are told time and time again “Oh, we don't usually see ‘them’ this bad this young”. You fill in forms over and over again highlighting just how ‘bad’ your child is. You are reminded constantly of the medical fragility of your child - you watch professionals not get too ‘emotionally vested’ in your child because even they don't want to risk the hurt of ‘losing yet another one’.

You are *trained not to dream* and  
coached to focus on *deficit*.

The reality is most babies won't grow up to be ‘exceptional’ or the ‘best in the world’ in their chosen fields. The majority of us, at best, hover around mediocrity throughout our lives and yet our most

vulnerable babies are denied the opportunity for 'big dreams', for 'irrational (but joyous) goals', or even the dream of 'mediocrity' that the rest of us enjoy.

### **But Mac had something to say... and thankfully, we listened.**

When Mac was two we decided long day care might be an option for him. I needed to do some part time work to be able to afford all the extra costs that come with a child with profound disabilities. And I needed some time away from him as much as he did from me.

Early intervention was for two hours each week in school terms - much of the time it was expected I should be in the room with him. He was an incredibly hard child to position - he had super rigidity and hyper-extension you had to see to believe. He literally did not bend in the middle. Couple this with the fact he had the potential to vomit at any stage (and with significant force) people always seemed to feel better if I was around.

Shawn and I felt he needed a more 'normalised' rather than 'specialised' setting - the specialised stuff we could, and were, doing at home. He was also getting quite spoilt because of all the undivided attention he received at home - he needed to have his world expanded.

The childcare centre where Mac's cousins went had a young girl with Cerebral Palsy (CP) about to start school the next year. She was in significantly better shape than Mac (almost everyone was). But we knew enough to be confident that their attitude was spot on. They had the right 'vibe'. I've since learnt the official terminology... they "GET IT". So, with the assistance of the early intervention centre, we arranged for some preliminary meetings.

This was an eye opener for us all.

Mac had not interacted with any of the early intervention staff in the entire time he had been attending the centre. He only tolerated being there, he wasn't his normal happy self, but he didn't scream - he literally just tolerated it.

So it was fascinating to see at the 'get together' at the day care centre that he responded to everyone who spoke to him. He either grinned at them or gave a verbal 'glll'. The early intervention staff were amazed. We had all noticed he sparked up at early intervention when he could hear the children at the pre-school next door out in the playground. He would spin his head in their direction and you wouldn't really get his focus back again. But here it was plain as day - this was a place he WANTED to be. These were people he WANTED to be with - so we applied.

Mac started long day care at the start of the new year. He attended twice a week for five hours a day. He had to leave early one day a week to go over to early intervention. This became more and more of a problem. Mac started to cry on arrival at early intervention and only smile again when we left. Why was I taking him out of an environment he loved for one he didn't.

#### **Why did the things he did at early intervention need to be in a segregated setting?**

Mac loves noise. He needs to be in a noisy environment and around children who can provide an appropriate verbal environment for him. What I witnessed in the "special needs environment" was that his peers with profound disabilities were all mostly non-verbal and immobile too - they weren't really learning from one another - we realised Mac was not benefitting from this environment (and he was of absolutely no benefit to the other kids). We acknowledged the reality there was some 'strength in numbers', support and understanding for, and from, the parents - but it's not about us

as parents, the decisions we were about to make, for Mac, had to be what's best for Mac.

We found out from an online parent support group you could apply for more funding so that Mac could attend long day care for more than five hours a day. The daycare centre weren't aware of this, but were happy to support our application. It seems ludicrous the Federal Minister for Family and Community Services needs to be 'bothered' with my child's application to access a private day care centre. It seems more ludicrous this information wasn't freely given to us or the day care centre as options we could pursue.

We were used to questioning things from a medical perspective. We had gone toe-to-toe with specialists who could have made bad decisions with fatal outcomes for our son. We researched extensively, we questioned, we queried (we still do). But here we were because of Mac about to essentially question "societal norms".

### **We started to question "where we'd been" and "where we were going"...**

There's a problem with extracting yourself from your 'old life' into your new 'disability-centric life'. You end up surrounded by people like you. People who, like you ARE EXHAUSTED and who are 'fully tapped resources'. Sure, there is camaraderie, understanding, great information to share and tips and tricks to pass on but this can be done electronically. This doesn't need to be your social network. Some of this group you would likely have been friends with had you met them under different circumstances, many you would not. You get lumped together because of the diagnoses of your children - not because you have common interests outside your kids.

You don't know how to get your friends to be involved and you don't know how to ask for help. Six years on we have realised just how important it is to maintain those relationships with your friends and family and are making a concerted effort to re-establish those ties or strengthen others. Many relationships remained intact (we have good friends), so it isn't as big a job as it sounds. Mostly it is about how we give Mac more freedom and independence to spend time with our friends and family members without us having to be there.

I know paid respite could provide some of this, but with the natural supports in place - respite is really unnecessary. And the connotation of 'respite' is that Mac can't have people in his life who simply 'care to care' they must be people 'paid to care'.

It is another seemingly innocent solution - carers get tired, give them respite. It pushes you back on that path of segregation, of difference... it doesn't create stronger natural supports, instead it has the potential to remove or diminish them. It sends the message 'you need to be trained to look after this one, it's tricky, it's hard and it's dangerous'. It shouldn't be this way - we need to be supported to maintain and develop MORE natural supports with grandparents, aunties, uncles, cousins, friends - we need to remove the 'fear factor'.

### **questions, questions, questions**

Like most people we hadn't really considered our stance on 'special education' before Meg and Mac. We both grew up in an era where almost all children with disabilities attended the local 'special school' - they weren't at school with us. But now we were asking: Why segregate? Who does it benefit? What is the back ground to it?

We had a little boy who really seemed to dislike his segregated early intervention setting. He wouldn't engage with any of the staff he was not his normal happy self. This was in stark contrast to mainstream daycare and pre-school - he loved it, it was obvious. He started making sounds in response to the other kids and staff, and would grin broadly when we pulled up in the car park each morning. This was amazing communication by a child who has little to no vision, no language and no independent mobility or purposeful movement. We owed it to him to pay attention.

We talked a lot about what we thought of the concept of special education (and early intervention in a 'special or segregated setting'). Someone had written in an article "**special education is a service, not a place**"... we agreed (and we could see the synergy between that statement and early intervention). While we are conscious everyone should be entitled to a choice about the best path for their children, we just couldn't see how not pursuing an inclusive daycare/preschool and then school setting could ever lead to an inclusive or mainstream life during or post school.

We were starting to think beyond the relatively short period of time someone spends at school. We didn't like the idea of anyone finishing school with their only option being to sign up for 50 years of 'day programs' and be surrounded only by people 'paid to care'.

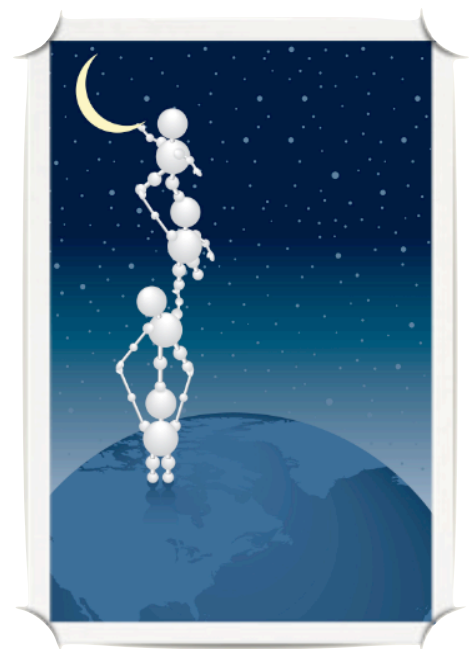
We **got off** at the **next stop**.

*fly me to the moon, or at least help me climb there...*

This was a major 'ah-ha' moment in our lives. We wondered how this kind of vision and life would be possible. We equated it to our own "moon landing" challenge. We compare it to the vision the Americans had when they were inspired as a nation to put man on the moon. How they pulled together, but more importantly, how they worked back, step by step from their vision to ensure they knew what had to happen to make it a possible.

This is where mainstream early childhood opportunities became so important. They are the stepping stones we needed to start this process.

I was fortunate to hear Concordia University's Assoc. Professor Tim Loreman speak and be privy to some further musings and conversations.



One of the key things he said was:

“Children **do not have special needs.**

They have **human needs -**  
to **be loved and love,**  
to **feel safe and welcome,**

to move about their environments

and to learn **to find their place in the world.**

“Special” are all of those

weird and wonderful things

we do instead of doing this.”

### how would this work...

We recognised for the USA to get man on the moon it needed the cooperation of an entire country. We needed no less from our community if Mac is to enjoy an 'ordinary' life. We certainly didn't need to reduce the size of "his community" or extract him from his able bodied peers into a congregated or segregated setting.

We were fortunate that we had already taken the first step by enrolling him in a long day care centre. Retrospectively, this was so important on so many levels - not the least being we had listened to Mac.

### Universal design for playing and learning

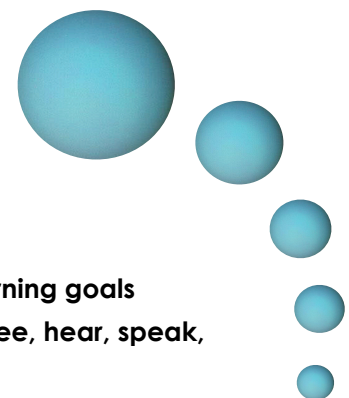
There is much talk in global education circles these days about Universal Design for Learning.

San Francisco State University defines it as follows:

**“Universal design means the design of activities that makes the learning goals achievable by individuals with wide differences in their abilities to see, hear, speak, move, read, write, attend, organize, engage, and remember.**

**Universal design for learning is achieved by means of flexible curricular materials and activities that provide alternatives for students with differing abilities.**

**These alternatives are built into the instructional design and operating systems of educational materials - they are not added on after-the-fact.”**





It's quite a mouthful. But here's the thing - they could simply be describing what happens in any early childhood centre, day care centre or pre school around the country.

And it is the key reason I believe early childhood is the right time to set the scene for inclusion. Because early childhood already does UDL best, it is innate and natural. Teaching occurs across the age groups and abilities, which in the early childhood period are significant. You have walkers and non-walkers, talkers and non-talkers and you include and engage appropriately.

In our instance, putting a non-walker and non-talker into the mix wasn't that 'dramatic'. Many of the younger children only had emerging language, many still had their dummy for security, lots were in nappies. So apart from the wheels, Mac didn't really stick out so much. Young children don't care about the disability - they just love having a friend who is unlikely to get up and leave when they are talking to him. They particularly loved in Mac's case he would never take a toy from them - he was a very good friend to the two year olds.

They didn't care that he didn't talk back, because, innately, they read his expressions. They knew his sounds and they assigned language to them. They knew to run and get his 'dummy' when he was upset or 'just looking like he needed a suck' (although we worked out that was particularly strategic on the part of one peer who had given up his dummy and appeared to be going through withdrawals, so very discreetly when getting Mac's for him he would have a quick 'fix' before handing it over). And they learnt very quickly to 'get out of the way... to save themselves' if he projectile vomited.

Mac is a very easy going child and seems to draw people in. He literally had 20 children vying for his attention the entire time he was there.

It was easy for him to meet any early intervention type goal in this environment, it was even better to identify when some of those goals were completely out of touch or had no congruency to what the other children were doing.

Particularly for Mac as a single child it allowed us to keep up with what was 'age appropriate' rather than him being treated as an eternal baby in the early intervention model. I still "marvel" at the desire the therapists had for him to be stimulated by a 'prissy star toy' (that any four month old would be bored with) when he was four years old. He had shown them his rapping drum, his crazy cackling Halloween pumpkin, his singing Spiderman, his obnoxiously loud hysterical monkey and his overly enthusiastic clucking chicken toys yet he was expected to respond to a 'baby toy'.

Mainstream early childhood settings were far more beneficial for Mac. The early intervention centre was still able to be used as a resource. To be fair, there isn't a lot of good working knowledge out there for kids as severely affected as Mac so I do understand why they were 'unsure' at times as to a projected path. But when you see the young kids interacting with a child like Mac, they don't define him by his deficiencies, they have no 'low expectations' or preconceived ideas - they simply embrace him and have no need to "fix him".

## Preparing for 'big school'

As we began to move towards starting school we spent more time learning and understanding how the education system works in NSW.

We attended the Family Advocacy seminars "One of the Kids" and "The Education Maze". Both of these were invaluable to give us examples of how Mac would fit into a mainstream class and also understand just how the NSW Department of Education works. We experienced yet another 'a-ha' moment identifying that, just as the other children would assist and facilitate Mac's learning, so too he would/could facilitate theirs.

This finally got us away from the mindset "will Mac in the class reduce the learning for the other children" which had kept 'popping up' and causing us to be a little unsure of our decision.

The final year before school started we added 'pre-school' to the mix for Mac. It was just down the road from his local school and allowed another group of children to get to know him.

This planning certainly made a difference to a smooth transition into school. Thirteen of the 40 kindergarten students knew Mac, some from day care and pre-school, some socially and one was a cousin.

For some he became THEIR safe haven as they clung to their friend in his wheelchair until their anxiety lessened. Some were very 'superior' as they explained why his "muscles don't work" and how he "drinks through a hole in his belly". A few who knew him very well were able to 'troubleshoot' if the staff had any problems with the tube feeding etc as the kids knew how to do it. This was strategic on our part, because, if the staff know a five year old knows how to tube feed, the 'fear factor' that seems to go with tube feeding will diminish.

We have had a reasonably smooth year with good working relationships between us and the school. It hasn't been without some problems, but nothing that hasn't resulted in better outcomes and process.

Just last fortnight we spent a week in Melbourne with speech therapist Rosemary Crossley. We had come to a stand still with communication options and unsure which way to progress. We were fortunate Rosemary was keen to take Mac on as a client.

We knew Mac had a yes 'facial expression' but we needed help with the next step of getting consistent yes/no options for him. We were starting to get overwhelmed with the choices in technology to better allow him to access more learning and increase his chances/options for communication.

Within two hours Rosemary had provided Mac a YES/NO option using two jellybean switches with his feet being the 'conduit' for his decisions. His cheeks will work equally as well, but as I was more unfamiliar with him using his feet we concentrated on them this week.

The rest of the week focussed on helping Mac develop a process for auditory step scanning.

With an older piece of technology, the Macaw 3, Mac is able to step through auditory choices with his foot until he gets the answer he wants.

Some of Mac's appointments went for more than four hours. He was incredibly tolerant and determined. I know in a week we have learnt more about communication options for Mac than the previous six years. But that's not to say we could have coped with this information all those years ago. It is timely now because, possibly, it is the right time. At times I am frustrated by the fact no speech therapist we have been exposed to until now ever truly aimed for independent

communication. Most people just get so overwhelmed with the complexity of Mac's physical condition they don't seem to know where to start.

It is generally assumed, based on his physical condition and lack of vision, there is most likely cognitive delays... and therefore he isn't given real opportunities for communication (until now).

Some of the questions Mac was answering were pretty interesting.

- We now know he is a Sydney Swans (AFL) supporter.
- He's pretty good with his numbers and knows that 2+3 does not equal 4, 7 or 9 but it does equal 5 and he knows 32 is NOT bigger than 43.
- He knows the wolf didn't actually eat the three little pigs.
- He knows which letter he needs to turn 'mat' into 'mate' and 'hat' into 'hate'... although he did suggest we ask him something else when asked to spell 'dog' (funny kid).

He did remarkably well on comparative relationships including:

- are watermelons bigger than apples?
- are lemons sweeter than chocolate?
- is night darker than day?
- are parents older than their children?

And even better on the passive relationship with questions including:

- John was hit by Eric, was Eric hit?
- Mary was driven by Alice, was Alice driven?
- Paul was chosen by Steve, was Paul chosen?

I would love to see every child/student have a goal for consistent YES/NO by any method as a basic requirement. Communication is power. Communication is opportunity.

Any centre and/or therapist (or even school) **who sets a goal below this should be challenged.** We all need to play a role in **demanding higher expectations for all children.** After all, the least dangerous presumption is that of competence, we all 'KNOW THAT'... now we need to 'DO THAT'.



## So here we are...

The proud parents of a kindergarten child. A little boy who is in a mainstream class and showing the way to strengthen connections and build his school community into an amazing, diverse, respectful and accepting place. A (very) little boy who, yes, is profoundly disabled but who is also robust, healthy, happy and has a penchant for pureed garlic prawns and Magnum ice creams. The only real downside - he is still 'nocturnal'.

Because of the opportunities ahead of us for communication (via AAC), Mac's world has just grown from one with reasonable but limited opportunity (primarily because we could see opportunities where perhaps others couldn't) to unimaginable and endless opportunity.

This is a wonderful place to be. It has taken six years to get to the place where we are **irreverently and fearlessly dreaming big, possibly irrationally but certainly joyously**. It's good fun, it's heartwarming and it's positive. I know we have many years ahead of us where Mac will be expected to be defined by his deficiencies because bureaucracy and funding allocation processes seem to require it.

We are here because we didn't take the expected path - thanks to Mac, we stopped and queried things along the way.

We can see so clearly the benefits of inclusive early childhood for all children, not just those with disabilities. I look at Mac's peers who excitedly tell me how Mac is a great dancer because 'his team won' the polka, or who get excited when, via his technology, he tells them about 'wombat poop' for news (and why it's square).

Mac has been described by some as "the most disabled child ever to be mainstreamed" - I don't know if it is true - it doesn't matter.

If it's true then he might just be the child who teaches the others the most.

Early childhood is absolutely the right time for inclusion. You and your daycare centres and pre-schools have an opportunity to lead the way for true social change. You have scope, free from curriculum limitations and over zealous bureaucratic interference. You can create the model for schools to follow.

When the schools complain, "we don't know how to do UDL", you can simply say "we do, we always have".

You need to help the families see the opportunities. Daycare and preschool gives us the opportunity to go back to work if we choose, it is absolutely 'respite', it is time out and it is normal. As Tim Loreman indicated... "we don't need 'special'".

# and the moon landing . . . how's it looking?

It's looking good.

Mac is a little boy who started life as a valued member of his community (albeit a rather fragile member) and who, because he isn't 'segregated' from his peers, should remain so.

Where he, with the right education and technology supports, can become a 'contributor' not a 'recipient'. Where he could be an employee or an employer, a car owner and a home owner.

**Mac is on track for a gloriously, ordinary life - which is all we seek.**

