

# **It Starts with Us! Harnessing Possibilities for Success and Belonging in Learning and Life**

## ***Keynote address by Lisa Bridle***

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Over the past two days, we have been challenged to think about how young people and adults with Down syndrome can be supported to live inclusive, fulfilling and productive lives. We have heard about what it takes for them to experience success in all areas of their learning and development, and how they can be supported to become valued and contributing members of their community.

The message of this conference “It Starts with Us” is both a challenging and an empowering one! To think that building a rich included life for people with Down syndrome starts with us can feel pretty daunting -- even if hopefully by now we feel a little more equipped than 48 hours ago. But it is empowering too – we don’t have to wait for someone else to lead the way. All of us have a part to play, and we can start today to begin to make our contribution – or to take our efforts to a new level.

We might all have a slightly different idea of what IT we are talking about but I trust that we can agree that people with Down syndrome are people of value and potential, deserving of lives which resemble the lives of every other citizen of this country.

If we want people with Down syndrome to take their rightful place as valued, contributing citizens, we must take a stand and say that everyone already belongs. Community inclusion does not require people to earn their place in the real world – to be “ready” or “good enough”. It is not just for the most able. It is not conditional, it does not end. Everyone who is born into this world deserves to belong and it is our job – as parents, as teachers, as professionals, as ordinary citizens – to make sure people with Down syndrome remain at the heart of community.

Today my task is to share with you some hard won insights from the last 2 decades of trying to create a rich meaningful life for my son, Sean, and to draw out some challenges for where we can start.

The first step – the absolute starting point – is crystal clear for me! IT STARTS WITH US really seeing our person with Down syndrome – our beautiful son or daughter, our student, our client, our neighbour etc. Seeing them as a whole person. Seeing them as they really are -- full of unique gifts, and not just needs or difference.

I know that this is the first step because during the first few days of Sean’s life, I did not see him, not really. As I was wheeled past my minutes old baby as he clung to life in the ICU, what I saw was a bright red swollen baby covered in bubblewrap, tubes and leads. What I saw was not my precious son, but Down syndrome writ large. For several days, this label stopped me from imagining

anything but gloom and disaster. It stopped me from recognizing that this was the same baby that I had eagerly anticipated. It stopped me from imagining any future which resembled life as I had known it. I was haunted by a recurring image of myself and an adult son with Down syndrome sitting on the couch, housebound and lonely – just the two of us – I saw in Sean a life of burden, isolation and restrictions. Looking back, I can see that I suffered a completely distorted vision which severely limited my imagination and skewed my anticipation of the future.

It was not until 3 days later when I got to hold Sean for the first time that I even began to truly see, to recognize the Sean in him – and not just the Down syndrome. There was a stillness in that moment ... even as the tears flowed. I felt for the first time since Sean's birth a sense of calm ... that things would be OK and that this small boy, my son, would teach me everything that I needed to know to be his mother.

When I managed to really see Sean– I saw a bright blue eyed baby who charmed me with his delightful smile and cuddles, who is among the most “attentive” and engaging people I have ever met. I was able to see him as one of us – his family – and not as somehow alien or other.

Since then, there have been many times when I have needed to remind myself to really look at Sean – to recognize him for the wonderful boy and now young man that he is – rather than allow my perspective to be clouded by the false perceptions of others.

When your child has a label you enter a world of diagnosis and a focus on deficit. I made a decision long ago never to allow this world to impact on how I see Sean. I refuse, for example, to pay any attention to assessment reports or plans based on deficit. Even if they are written for a good purpose, they are usually close to slander because they are so lopsided in focusing only on needs. Sure Sean has needs – as we all do – but I have learnt to resist seeing Sean through this lens. Instead, it is always my job to see Sean with my mother eyes – and to then loudly profess his beauty, talent and potential to the world. I am not always successful in getting others to see what I see – but at least I can protect myself from having my view of Sean contaminated.

So why is it important to really see our family member? Mark Twain has said: We cannot depend on our eyes when our imagination is out of focus”

Sadly in our culture, most of us come to the experience of disability with our imagination out of focus and our vision clouded by stereotypes and perceived limits. People with disability are still commonly seen as burdens, as objects of pity, as nuisances or menaces, as inferior or lesser – and none of us are immune from the effects of these stereotypes. We WILL come up against these stereotypes and attitudinal barriers. And even in us, the remnants of these stereotypes can sneak up, planting seeds and doubts, undermining our confidence.

To get our imagination into focus we need to be conscious of these myths and focus so we can always see our family member for who they really are and, with that, be ambitious in our hopes and dreams for the future.

Seeing Sean as he is now means I see a wonderfully funny, sociable and generous young man with a great spirit. He has considerable gifts -- as the family entertainer, reconciler, and perennial party

boy. He has enormous courage and resilience and incredible empathy. He makes you feel like the most important person in the world and keeps us endlessly amused.

I see a young man who wants very much to enjoy a life just like his brother and sister -- at the centre of things. And with this focus, I am able to imagine MORE for him. I am able to hold onto a vision of what I know his life should look like:

- Regular – just like his sister and brother!
- Lots of friends and other relationships
- A real job and a good income
- A chance to keep learning, exploring and developing
- A home of his own
- A strong sense of self and making a contribution
- Holidays and adventure

### **IT STARTS WITH US IMAGINING A LIFE OF RICHNESS AND PURPOSE AND CONTRIBUTION.**

Imagining and dreaming of a life of possibility is helpful because we can reclaim our ordinary dreams and because it tells us where we want to end up.

My dream is that Sean will have a rich life, full of opportunities to learn and contribute, embedded in a community where he is valued and able to experience love, belonging and a strong sense of his own worth. I want more than a mediocre life or a life carved out in a parallel disability world.

Being clear about the life Sean deserves is the antidote to all the “they will never”, “you need to be realistic”, “people like that” stories that still get told!

Sometimes parents are dissuaded from their hopes and dreams because the developmental future of their child is uncertain – but everyone’s future is uncertain! Hope and high expectations give all of us the energy we need to build that future – and I would rather deal with the disappointment of a few plans that didn’t work out than live a small life never daring to dream big.

If go with a dangerous assumption like “they’ll never live independently...”, we risk undermining the possibility of maximum independence. Instead, we need an optimistic form of realism that says, “I don’t know what supports my son/daughter might need to live independently, but we will work towards this goal, and then figure out how and with what support that could be possible.

For professionals too, it is helpful to have a positive vision of what your student or the person you work with can achieve; what their life can look like. We must then surround ourselves with allies who exude positive expectations and avoid those who are keen to play the role of wetblanket and naysayer.

We have a choice – will we be someone who sustains hope or crushes it?

And we should remember that both can be absolutely life-changing for the person and their family.

A parent leader I know, Margaret Ward, says that all of us need a vision that scares us – a vision that is constantly expanding to new possibilities. One of those elements for me was hearing years ago that students with intellectual impairment were regularly included in university – participating in mainstream academic courses and campus life and graduating – not necessarily with degrees, but with their own achievement certificates. At the time, I wasn't sure that was going to be possible but I did think "Well Sean sure can be fully included in Year 1!" Now it is clear that this is exactly Sean's expectation for himself – and one of my great dreams is that this could be possible for Sean.

For us, being included in mainstream school was an important part of our vision for Sean. Because we wanted for him to be absolutely embedded in his local community, he needed to be there to the maximum extent possible. Sean progressed through childcare, kindy, preschool and primary school alongside neighbourhood children. He participated fully in the shared life of the school -- everyday classroom activities as well as excursions, assemblies, school concerts, sports days, school camps, etc. He had playdates, attended and hosted birthday parties, and with classmates and neighbours participated in soccer, swim club, circus classes and martial arts.

Through this, Sean has laid the foundations for enduring friendships, as well as developing a strong sense of himself.

Our dreams for Sean – knowing where we wanted to end up -- helped us to steer our course. The vision was our compass, helping us decide where we would invest our time, it set our bottom lines and priorities.

Of course, many will dismiss our dreams. Some of the naysayers will be polite and relatively innocuous but others will be hurtful, even cruel– and place real barriers in our way. So while it might start with us really seeing the person and daring to dream big, but once we know what we want, we must build our courage to pursue that.

### **IT STARTS WITH US BUILDING OUR COURAGE, REFUSING THE OFFER OF A "SMALL" DISABILITY DOMINATED LIFE – FOR OUR CHILDREN OR OURSELVES.**

I don't know about others in the audience, but I was unprepared for how vulnerable you can feel as a parent – with Sean, this vulnerability was exaggerated ten-fold! Weight gain or lack of it, developmental milestones, his early medical challenges – all were cause for great anxiety, but this all pales in relation to my great fear that he will experience rejection – that he will not be appreciated and welcomed. Sadly this fear is not an unrealistic one – he has been rejected by some, he has been set up, made fun of, treated as "lesser". This is painful but I remind myself that rejection of some kind happens to all of us at some time – it is possible to survive!

Historically, of course, people with Down syndrome have been shunned, consigned to institutions and subject to abuse and neglect. The legacy of this history of devaluation and rejection persists – albeit more subtly --- small children told they cannot attend the same school as their brothers and sisters or always being directed to the "special teams, "special clubs" and "special events" reserved for people with disability.

Facing this reality is not, however, cause for despair but for clear thinking. Knowing that we have an historical habit of separating children with disability means we can be more prepared.

Sean has the right to an ordinary 20 year old life – but pursuing this still has the capacity to terrify me! I can still find myself immobilised by fear that Sean will be rejected or be in danger, even though I have evidence of that he is very capable and also that community is mostly a welcoming place. Planning parties, helping Sean to invite a formal partner, turning up to enrol in a regular school, signing Sean up for soccer club or a TAFE course have also taken some courage as we risked rejection. But, while often there have been uncomfortable conversations (particularly with prospective schools), what wonderful opportunities we would have missed if fear had had the last word.

I have learnt that as parents we need to grow a thicker skin at times, to go where we are not immediately welcomed and to persevere – rather than retreating into what seems safe and non-threatening. For teachers and professionals, courage is also needed. To be Ok with feeling out of your depth, dealing with challenges for which you feel unprepared. Influencing colleagues, parents and students and leading change in your school community can all take courage.

There is also the courage it takes to “let others in” by sharing our vision and also the courage to “let go” --

The “first times” – finding his own way home from a new place, taking the bus, dropping him off to line up with his ID at a pub or nightclub with seemingly hundreds of other young people – have all been scary – this last one particularly so on the night he turned his phone off and refused to come out at the agreed pick-up time. While I was dealing with my worry, he was, of course, meeting attractive young women to add to his phone or Facebook contacts!

In Years 9 and into Year 10, our courage was greatly tested. The playground was pretty “Lord of the Flies” and Sean was struggling with how to make friends in appropriate ways. We were called to a series of school meetings where it was patiently explained to us that our chosen school was not right for Sean, and so they would provide a list of appropriate schools – “protective environments” – which would better suit his needs. While he always had many great teachers and allies, others appeared to judge us as hopelessly unrealistic parents who were choosing to disadvantage our son and burden the school. We also experienced (however unintended) a painful dismissal of our view of Sean as a precious, wonderful boy with the same life aspirations, the same need to belong, and the same capacity to contribute to and benefit from the ordinary rituals of high school.

I lost a lot of sleep over those months, I dreaded the calls and the meetings where I would need to muster up all my strength to advocate for Sean. It was a heartbreaking time but strangely I was also completely at peace with our choice. Despite Sean’s struggles, on most days, he strode into that school with a stubborn confidence, and I had great faith in him and his capacity to weather the storm of adolescence, and of those tricky and challenging times.

While disappointed with the school’s response, I understood that this was a steep learning curve for the school. I stayed committed to having a positive relationship with the school and accepted

the reality that, after centuries of exclusion, the inclusive path is not always easy – but always worth taking. I also learnt the truth that Eleanor Roosevelt has captured when she says:

*We gain strength, and courage, and confidence by each experience in which we really stop to look fear in the face... we must do that which we think we cannot.*

## **IT STARTS WITH US CLINGING TO THE ORDINARY**

What I have been talking about is really the value of clinging to the “ordinary”. I felt this quite early when I realised that Sean did not need fixing, and while we would dip in and out of disability specific support or therapies as needed, as much as possible we would try to take the most ordinary or typical path. I did not want his memories to be of “therapy”, but ordinary play. I didn’t want his life to be dominated by interactions with professionals or other adults at the expense of the simple joys of childhood. I also discovered that you can get a lot of “therapy” at the park, at the museum, and at the pool!

If we want our family member to remain at the heart of community and not at the margins, we need to on guard against being seduced into the disability world unnecessarily. Just because the doors of this “special world” are more easily open to us – and because of historical habits – the place many expect us people with disability to be – does not mean this is where people with disability are safest or best placed. I decided that I would not trade Sean’s place in the regular world for the sake of a ready welcome. Instead I would try to keep him where we wanted him to end up – in the regular world – even if that seemed at times a harder path.

I want here to acknowledge that people make different choices or are forced into different choices. And life is full of compromises – this is as true for our family as for others. Sean currently attends a disability service for literacy classes one morning a week and this has certainly provided him with a continued opportunity for learning. Clinging to the ordinary is a principle but not a judgment at all. Our choices are also a reflection of our vision based on knowing Sean and what we believed was in Sean’s long-term best interests.

Sean attended a Catholic boys’ school of over 1400 students – it was in walking distance of our home.

In his senior year, he studied a range of Art, PE, English, Maths and Religion, as well as undertaking work experience. He always loved school camps, he proudly displayed his art and photography at the Art show, he was part of the cycling team and personally raised over \$1000 in the MS Brissie to the Bay ride. He was a faithful supporter of the weekend school sport. He took his great friend, Harriet, to both the Semi and Senior formals and post-formal parties – something that involved nightly phonecalls to Harriet to make sure she was ready!

I have already spoken about the tricky years. While a number of strategies were utilised to get back on track, and there was a big turnaround with his and the other boys’ greater maturity, the best thing for Sean was joining the rugby program – travelling to training sessions on the school train with hundreds of other boys and participating as a supporter and water carrier for one of the teams. This participation and formal role with the team had an enormous impact on his sense of

belonging and addressing the previous issues at school, and many of his rugby mates continue to be close friends. This turn around showed me that it was figuring out how Sean could more fully be an ordinary member of his school community – and doing this by pursuing the regular ways other kids make friends – through shared interests and participation -- rather than any specialist intervention or support that made this more possible. Many parents report that there can be a “kick them out” point in many school inclusion stories – ideas that the “gap is getting wider” or that inclusion is becoming more difficult. These challenging times are exactly the times when we need to redouble our efforts in really seeing the person, holding onto our vision, being brave and clinging to the ordinary.

At the beginning of Year 12, Sean also turned 18 and when I saw him on that night surrounded by more than 50 friends – from both primary and high school – I was reinforced in my confidence in our choices. Sean’s complete joy was palpable, particularly when insisting on gathering the boys of his school to sing the school song.

And then suddenly it was graduation! I was extraordinarily proud of the maturity Sean displayed, as he walked amongst his classmates shaking their hand, congratulating them, and then embracing the closest of his friends in a big bear hug. He was absolutely working the room! He was an enthusiastic participant in singing the school song and warcry which was conducted on the oval in pouring rain just to add to the atmosphere! He attended the graduation party and then he was off to Schoolies where he attended the beach parties and drank beer with his friends at their units – he was one of the few legal 1s.

He left school with a strong sense of himself, a pride in his school and loyalty to his tribe! He has great mates with whom he shares great history ... friends who are future plumbers, electricians, builders, doctors, lawyers, engineers, and teachers!

Being embedded in “the world of the ordinary” means that others are also on the look-out for opportunities for Sean. A year ago, I had a call from the mother of Sean’s close friend who explained that the gang had also been thinking about how Sean could stay in touch with his friends and wondered if Sean would like to have a role with the local rugby club where many of the boys still play.

So last year Sean attended games and running the water. I can’t tell you how wonderful it is to know that others – his friends AND their parents – are also thinking and planning for Sean and how he can maintain friendships.

### **IT STARTS WITH US MAKING RELATIONSHIPS AN ABSOLUTE PRIORITY**

It is a sad reality that many children and adults with Down syndrome lack real friends. There is a persistent damaging myth that there is nothing we can do to make relationships happen. If nothing else, I want you to know that paying attention to relationships STARTS WITH US. It starts with parents and teachers and ALL of us who say we want the best for people with disability. And we must make relationships an absolute priority because, in the end, relationships are what make life worthwhile.

Ok, so we can't manufacture friendship for anyone, BUT we are not powerless either. There is a lot we can do to make relationship more possible, and it starts with avoiding all the things we currently do that makes friendship more elusive.

The first mistake we make is: not believing friendship is possible. WE make this mistake when we only expect people to stick to their "own kind" meaning other people with disability or see the lack of friendship as sign of its impossibility.

The second mistake at least for parents is being so ruled by our fears that we do not notice the people who are open. If we don't notice the offers of friendship, we won't nurture those early seeds of friendship which may take some time to develop. Believing friendship is possible helps us take the risk of opening up in the ways which make friendship more likely to develop.

Over the past couple of years, I have been very conscious that the signs of who would be lasting friends were actually there from the very beginning ==while not all friendships last – people move away or interests diverge, and some new friends emerge -- I can look at photos over the years and see the start of friendships. Now that I am more conscious of the signs, I know that extending the hand of friendship early can make a real difference.

The third mistake is removing young people with Down syndrome from their peers – we can do this when we end up in separate places –the special world –but we can also do this when WE become a barrier. We are the barrier when parents are always there rather than leaving a space for others. We are a barrier when adults are the partner for school activities, or a support worker or aide plays a role of companion rather than connector. WE NEED TO MAKE A SPACE! When a person will experience more difficulty in making friends, we must also recognise that we do them a great disservice by not allowing them to participate alongside their peers for the maximum time possible. While no guarantee, friendships are likely to be strengthened by being included in regular classrooms, regular sports, regular cultural groups and more. I know many of you will be thinking that inclusion is good but withdrawal is needed if we want students with Down syndrome to learn effectively – that the one on one time is critical but my experience was that Sean's greatest role models and motivators were his peers, and in any case, as a friend says: "You can have a good life without ever learning to read, but you can't have a good life without friends". Now I think – as she does – that you can have both but prioritising relationships is critical.

The fourth mistake is not recognising both how long it takes to make a friend (at least a lot of the time) – Inviting others to do things, suggesting shared activities, asking people to spend time, helping Sean to be a good friend, being an ambassador so Sean is better understood and more likely to be perceived positively, building a bridge by helping others connect with Sean through common interests -- these all make a difference. It is critical for us to become good community detectives – scoping out opportunities and roles for our person to connect with people they are likely to click with and then following up those people who are open.

Friendships are precious so we need to work to sustain them. Sean needs support to hold onto friendships – his communication can be hit and miss, his capacity to make plans to connect with friends (while improving all the time) mean that these can stall. The busyness of life and the very

ordinary experience of friendships withering over time if people are not thrown together means we need to be very conscious of helping Sean hold onto as many of his good friends as possible.

I expect that everyone needs to find the way to hold onto friends that works for them but we have what I like to call the party strategy. WE also help Sean to be a friend to have friends – meaning being a thoughtful birthday card giver, an enthusiastic welcomer and a generous caller or staying in touch via Facebook.

What I do know is that Sean has friends who have appreciated him since he was 3 or 4.

This from his friend Rachael: Sean, you are such an amazing person. I remember being in grade 1 with you, you were and still are always so happy and fun to be around.

And from Harriet: Having you in primary school made it so much more fun. You have shown me how to have fun when life is boring. You have taught me a thing or two about dancing. And finally you have shown me how I can find something good about every day. Thanks you for just being you!

### **IT STARTS WITH US BUILDING A COMMUNITY AND BELIEVING IN THE CAPACITY OF THE COMMUNITY TO WELCOME AND INCLUDE.**

I have already spoken about my fear of rejection but though community can be unwelcoming or disappoint us, it can also be wondrous.

As with relationships, we can also do things which make it more likely to find welcome rather than exclusion. Key to this is helping your person be known, and sharing the vision.

We have been fortunate to live in the same geographical community for almost 30 years and Sean is well-known and regarded in that community, and almost every day I am conscious of the value in creating the web of relationships we desire.

Because I grew up in a country town, I think trying to find the “village” within the city made sense to me. Being known and knowing lots of people gave me a secure identity growing up and I sought that for my children as well.

As a family, we have always tried to be active and visible in our community. As a former community development worker, I knew that building strong relationships is aided by geographical proximity and regular presence. Setting our compass to local where possible helps us to form the web we want for Sean. Sometimes when we hear of a new activity starting up across town, we have thought about our limited energies and decided we would concentrate on Sean being known where he lives.

The benefit of this is he has school friends who work at the gym he attends, he swims alongside other friends, he has workmates and fellow youth group members who know him or our family from when he was much younger. People from the vege coop where he volunteers also play social Frisbee with him. Many live within blocks of our home.

Being known in his local community has fantastic spin-offs. It certainly makes it easier to take the risks of exploring new opportunities as you are approaching people who you already know. A good example is the church youth group Sean started attending in about year 10. We are not Anglican

but Sean went to school with the youth group leader's son. This made joining the group much less daunting. What we have experienced in this ordinary place is how possibilities expand. He started going once a week, and now he attends the senior discussion group every fortnight and socials (movies, dinners, swimming parties, bonfires). Older members of the youth group play social Frisbee every fortnight which Sean enjoys, and now he has become a youth group assistant and hosts the senior youth group in our home every fortnight – a great role which suits his great gift of hospitality. Both of these roles – assistant and host – like the role with rugby were suggested by others who were also thinking about Sean and how he could continue to grow and develop – and importantly live a more meaningful life through contribution.

This happened because he was known and he was known not for having Down syndrome but for his gifts and our vision for him.

### **IT STARTS WITH US PLANNING FOR CONTRIBUTION AND BELONGING AND NOT A TIMETABLE**

Sean is currently:

- Son, brother, grandson, nephew, cousin, and god father
- A home cook and cleaner
- He is a keen camper, photographer, movie goer and party goer.
- A helpful neighbour
- An employee, co-worker and operations team member
- He is a swimmer, a gym member, a ju-jitsu practitioner, a water carrier for rugby, a social Frisbee player and sometime hip-hop dancer and social soccer player
- As already mentioned, he is a youth group assistant and host of the fortnightly seniors youth group
- A vege co-op member and weekly volunteer
- A faithful friend
- A keen Facebooker and instagrammer and avid Neighbours fan.
- A world traveller

Sean has been out of school for 12 months and celebrates his first year of employment this week. His life is very full but undoubtedly the highlight for him is his 3 morning a week job. His employer is a large community organisation in walking distance from home. He works under award pay and conditions and outside the supported wage system. This job was developed for Sean because a member of our support circle saw a match between Sean's skills and potential jobs in her workplace -- but it wouldn't have happened if we hadn't had the expectation Sean would work, if we hadn't been clearly focused on what Sean would offer to a workplace and if we hadn't started

sharing our dream and expectations with our friends and allies and preparing him for an expectation of work.

It would not have happened if we had accepted the advice from school to focus on sheltered workshop options or been discouraged by Sean's first employment consultant who explained that Sean would be very hard to place, and anyway he could stay on the pension and never need to work. Because she didn't really believe Sean was employable, she told me very condescendingly that I was "thinking like a mother" in talking about his potential for work – clearly code for being deluded. She seemed quite confident of her point of view – after all she had known Sean for 30 minutes and I had known him for 19 years! It took some courage to confront her and then to lodge a formal complaint -- not knowing what the reaction would be, but luckily the service took us seriously and his subsequent support by the employment agency has been exemplary.

Sean goes off neatly dressed with his ID badge and swipe card, texts me photos of his workmates, and is learning new skills in administration (photocopying, laminating, shredding), car-cleaning and a range of other operational support roles. He has a role maintaining bathroom and kitchen supplies, and also assisting with shopping. On Thursdays he helps to serve a BBQ for clients of the service.

This job could not be a better fit for Sean – it is a large organisation – more than 150 employees and always something happening. I do think he may have the best job ever!!

It is warm and welcoming and creative. There is always something fun or stimulating happening – festivals, retreat days, staff days which include the usual talkfests but also Bollywood dancing and meditation.

Sean may not have great money skills but he looks forward to that fortnightly pay slip and he walks out the door with a real sense of purpose, looks forward to buying a flat white from the coffee van alongside his work colleagues. In every way, he is included as a regular employee – attending staff supervision, participating in staff training and retreat days. He has his own work email address which goes directly to his iPad and he tracks his appointments in his electronic calendar. He enjoyed two staff Christmas parties – soccer zorbing with his operations team, and winning Prom King at the all staff Ball. The greatest thing about his job is not however, the pay or the perks but being surrounded who really get what Sean has to offer. Recently I received a text from his boss out of the blue saying "Thanks so much for giving birth to Sean and especially for bringing him into my life".

### **IT STARTS WITH US REMEMBERING TOGETHER WE ARE BETTER.**

I short-changed Sean a great deal in the early days by anticipating only the worst.

Getting a rich, ordinary and included life does not happen without many challenges, but we are stretched, not broken – and the stretching seems to have strengthened rather than weakened us. I have learnt the value of insisting on a BIG life, a life of adventure, a life at the centre. This is, however, not a happy ever after story – there are always things to work out, we do not have a

perfect replica of our vision. There is still a gap between Sean's life and the life of his siblings .... But we are on the road to where we want to be.

So far what has kept us on that road is surrounding us with those who share and bolster our dreams. I have found that TOGETHER WE ARE BETTER.

At the time of my birth, babies with Down syndrome were mostly institutionalised; only a few brave families resisted this path. Children with Down syndrome were considered ineducable; they were denied life-saving treatments and no-one expected them to learn to read, study, work, live independently, marry or do most of what we now know is possible.

I pay tribute to those brave pioneering parents who made Sean's life possible.

Our challenge now is to support each other to keep dreaming of better lives for people with Down syndrome -- to keep seeing possibility and to keep celebrating all that is wonderful, unique and inspiring about individuals who happen to have Down syndrome. As parents, we need to be there for each other in the good and hard times. For those of you who walk alongside people with disability and their families, we need you to be there sharing our dreams, helping to fuel rather than dampen these hopes.

Sean is not his disability. He is a funny, generous, enthusiastic and outgoing young man who engages life with a vigour and attitude that shakes us all up. EVERY day, my beautiful son teaches me to be strong, to be brave, to be determined, and to go into the world with a big smile and an open heart.

A rich included and successful life is possible. It is possible for everyone to be valued for their contributions and to experience love and belonging. But, it won't happen without changed mindsets, better imaginations and learning to be brave.

Moving towards this possibility depends on US! It starts with us, it ends with us – and by making a start TOGETHER, I believe, we can make this rich meaningful life possible for all people with Down syndrome. Let's START!