

One small step

A MOTHER'S QUEST TO GET HELP FOR HER DISABLED CHILD HAS RESULTED IN A PETITION TO FEDERAL PARLIAMENT.

Story: Georgie Oakeshott Photography: Iain Bond

Three year old Sebastian is learning to talk, walk and recognise colours but it's harder for him than most other children.

Born with intrauterine growth restriction and a severely obstructed airway requiring a tracheostomy, Sebastian spent the first four months of his life in intensive care. He has had multiple operations and more tests and procedures than most people experience in a lifetime.

A happy, easy-going little boy, he is still very weak, is fed with a tube and has been diagnosed with a long list of problems including global development delay.

But day by day, little by little and thanks to a rigorous schedule of treatments and therapies, hard working Sebastian is making progress.

He can't walk or crawl yet, but he recently learnt to pull himself up from sitting to standing much to the amazement of his proud and patient mother Melissa.

Since bringing him home from the babies ward one month shy of his first birthday, Melissa Foreman has focused on maximising Sebastian's opportunities for learning and development. A trained nurse, she knows these early years

represent an all-too-brief window of opportunity to develop potentially life-changing skills.

Determined to do everything she can for her young son, Melissa's weeks are spent on an exhausting round of hydrotherapy, physiotherapy, speech therapy and conductive education sessions, which at one point were costing her \$400 per week.

"Because he was never given a label he misses out"

"Parents in my shoes will do anything and try anything for their child if it means even the tiniest step forward," she says.

This determination has led her to the federal parliament, with a petition she organised calling for an end to the uneven funding arrangements currently in place for children with disabilities.

Melissa's petition with 2,261 signatures calls for urgent reform to the government's Better Start program, which provides assistance for early intervention treatments and therapies — but only for Australia's estimated 9,000 children with cerebral palsy,

Down syndrome, Fragile X syndrome and sight or hearing impairments.

Introduced in July last year, the Better Start initiative gives children in these five categories up to \$12,000 to help pay for treatments and therapies widely recognised as playing an important role preparing these children for school, reducing their need for special education, improving IQ and reducing behavioural difficulties.

Melissa's petition asks the House of Representatives to take all the necessary steps to act urgently and effectively to amend the Better Start policy so there is no longer inequality of access. It asks that the current eligibility criteria be revised and replaced with a needs based model where eligibility is determined by the functional aspects of a child's disability, the level of impairment and how the impairment affects the child.

"Sebastian has all the same mobility and learning difficulties as children who are eligible for funding, but because he was never given a label he misses out. I remember sitting in a room with all these children and their parents and they were so excited about the \$12,000 they were going to receive — and there I was, the only single parent and the only one not getting the funding. I felt isolated."

Despite feeling segregated, she's definitely not alone. Her petition gives voice to the concerns of hundreds of other parents calling for a needs based model. With a Facebook page and a video on You Tube they criticise the current eligibility criteria as "representing exclusion".

"It infuriates me that the government can say in the promotional material for Better Start that 'every child deserves a better start' yet only invest in those that they deem worthy or cost-effective," Melissa says. "It makes me feel very sad and ashamed as a mother because all you want to do is protect your child from this kind of discrimination."

Despite an initial reluctance to organise a petition because of the limits on her time, Melissa decided it was a good way to try to bring about change so that all children with disability receive the financial assistance they need and deserve. But any changes will probably be too late for Sebastian.

"He's three years old now and you must catch these things early," she says. "By the time he's five it will be too late. All the literature shows that regardless of the diagnosis, even for a normal child, early exposure to treatments and therapies is the key to bringing the best outcomes."

"In our case that's physiotherapy, hydrotherapy and conductive education [CE] — which is a holistic therapy focused on walking, standing, sitting and even learning colours and shapes. It incorporates speech, music and singing, so it's really enjoyable for the child but they're also working really hard."

"Sebastian really responds to CE. I've seen an amazing difference. Initially he wasn't able to sit or stand, but now he can pull himself up from sitting to standing. I've noticed he learns more quickly when I sing to him and I've seen an amazing improvement in his motor skills, and his cognitive skills are improving as well."

A single parent on a carer's pension, Melissa has had to accept there's a limit to how much therapy she can afford. Sixty dollars for a physio session plus another \$60 for a hydro session plus \$100 for CE and \$140 for speech therapy quickly adds up.

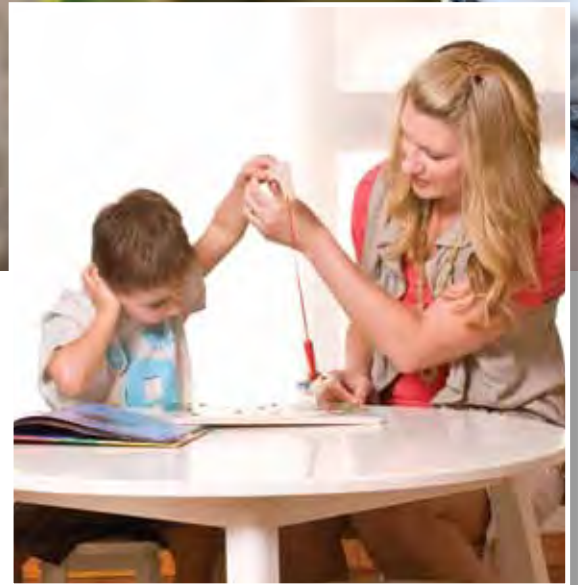
"We had to cut back to just one session of CE each week, which was a difficult decision because he really enjoys it and it's where we have seen the most improvement. That's what I would've used the Better Start funding for."

Along with the other benefits such as preparing a child for school, early intervention may also reduce a child's dependence on costly specialist services later in life. According to one early intervention organisation, for every dollar spent in early intervention there is a saving of \$700 to the community.

"Sebastian has so much potential. I hope one day he will learn to walk and control his weak muscles. I hope that he will learn his own way of preferred communication, whether that be signing, picture cards or even talking," Melissa says.

"I hope that one day he will be able to say 'Mummy' — that would be a dream come true. All the firsts people take for granted are what I will cherish whenever Sebastian chooses to make them."

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EQUAL CHANCE:
*Some disabled children
are missing out*

A government response to Melissa's petition was tabled in the House of Representatives by the chair of the Petitions Committee, John Murphy (Reid, NSW) in February.

The response, from Parliamentary Secretary for Disabilities and Carers, Senator Jan McLucas said the government recognises there are other conditions which may benefit from early intervention and highlighted the work being done towards the development of a National Disability Insurance Scheme. Senator McLucas also referred to a government commissioned KPMG report which



recently recommended expanding the Better Start program to include children with eight chromosomal conditions and microcephaly.

Melissa says this would be great news for those families, but would still leave Sebastian excluded.

“The KPMG report refers to eight chromosomal disorders and microcephaly as being the conditions that will ‘cost the least, in terms of their incremental impact on Better Start’ which irks me no end when speaking of any child’s future and worthiness,” she says.

When her petition was tabled by her local member, Kate Ellis (Adelaide SA), who is also Minister for Early Childhood and Childcare, Ms Ellis acknowledged the need for reform.

“Australia needs a disability services system that provides care and support based on people’s needs, not a lottery of what kind of disability they have, how they acquired it or where they happen to live,” she told the House.

“We understand the current system for caring for and supporting people with disability is not working for everyone. Sometimes we just have to face up and admit that. I know that for many people with disability and their carers, providing care and support is a challenge.

“I am pleased to be able to provide a voice for a local mother in the electorate of Adelaide, which I am lucky enough to represent in this place — Melissa — who is dealing with this challenge on a day to day basis. I want to place on the

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record my absolute admiration for the work that Melissa does in providing care for her son, Sebastian.

“Melissa is also a passionate advocate for ensuring that all Australian children with disability receive access to effective treatment and early intervention services. She has been incredibly hard at work collecting signatures right across Adelaide, in the suburbs and all of the streets.

“We know that people with disability and their carers deserve the same opportunities, and I am pleased that our government is working hard to deliver real outcomes in this area. We know that there is more work to do but we also know that for every story like Melissa’s — the incredible courage she displays day in and day out — there are thousands of families just like hers right across Australia. I am pleased to table this petition on their behalf.” •

For more information on petitions to the House of Representatives visit www.aph.gov.au/petitions or email petitions.committee.reps@aph.gov.au or phone (02) 6277 2152.