

Children, disability, health, education and the federal election

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As far as I know and thanks to Bill Shorten, this is the first time services for children with a disability have been raised during a federal election. Tony Abbott was quick to respond. But their promises lack the practicality needed to win my vote. Please let me explain why.

Our community has to decide how it will support people with disabilities. Governments and much of the community want to include people with a disability in the community. The challenge is how to provide or fund any extra service and support needs that arise from their disability.

At present, a damages or insurance pay-out may give a degree of independence to a few people who can show that their disability is due to some form of negligence or fault.

But many people with a disability are second class citizens who depend on the charity of others; usually their family. They do not have the financial resources to buy the services and support they need. Most people with severe or profound disability have needs that exceed the capacity of their family to support them.

As Australians, we want people in our community to live with dignity. We do not want anyone, especially people with a disability, having to communicate their needs directly with their local community and obtain funding through begging on the streets. We prefer to provide support through governments, philanthropy and charitable organisations.

People with a disability depend on Governments to ensure their essential service and support needs are met ... and to help them participate in their community and live with dignity. Philanthropy and charitable organisations do a great job but it is not practical to expect these sources to guarantee they will meet all the needs of people with disabilities or share their proceeds in a completely equitable manner.

The proportion of our population with a disability and the severity of their disabilities are both increasing. There is widespread agreement that services, care and support for people with a disability are seriously inadequate. And the need for disability care and support is increasing.

So there is a problem. Government funding for disability services, care and support has to increase but politicians in the major political parties prefer to decrease taxes and Government spending, believing this is what most Australians want. Politicians do not want any talk of "a big new tax" ... especially at election time.

Most Australians want to improve the quality of life for people with a disability. This involves both investment and just doing things better (often the result of research). We want people with a disability to be better educated, employed and live independently. We do not know whether investment in these areas will be economically beneficial but we believe better quality of life ensues.

The prospect of a national disability insurance scheme, the big issue for people with a disability, their families and carers, is in the hands of the Productivity Commission. This is a big idea that will need comprehensive support from government and from the community. Fortunately it will not be discussed or decided in the heat of a federal election. This issue deserves careful consideration in a climate where bi-partisan consensus and support is possible.

There are plenty of other issues relevant to people with a disability that deserve attention in this election campaign. So far, the issues relating to disability that this election touched on include early intervention for young children with disabilities and in-school disability services. Research shows:

- infants and young children with long-term disabilities can benefit substantially from appropriate treatment and rehabilitation, often in the form of clinically supervised early intervention; and
- many students with a disability need additional services and support in school.

So the major parties are thinking in the right direction.

My personal focus is people with autism spectrum disorders, a group whose numbers have more than doubled every 5 years for at least 20 years. If this doubling in numbers continues for the next 5 years, there will be more school students with autism spectrum disorders than there are children with intellectual disability. And if autism diagnoses continue to double for the next 10 years, on average there will be at least one child with an autism spectrum disorder in every school class.

Data in the 2003 ABS disability survey show that 87% of people with autism have severe or profound disability: a higher level of severe or profound disability than is found among people with intellectual disability, sensory impairment, or any other of the identified disability categories. According to the diagnostic manual, autism diagnoses are for people with "severe and pervasive impairment" ... pervasive means "all the time", not episodic disability, as is more usual with mental illness.

Children with autism traditionally missed out on many essential services. Concerned by this oversight and on expert advice, the Department of Health and Ageing advised the community (politicians, bureaucrats, clinicians, service providers, families and carers) in 2006 that each child with autism needs a minimum 20 hours per week (1000 hours per year) of intense autism-specific early intervention for at least two years (see <http://tinyurl.com/3ygtzcr>). Over 24,000 people (representing a significant majority of families affected by autism) endorsed this through the 1000 Hours online campaign (see <http://www.1000hours.com.au/>).

Just before the 2007 election, John Howard announced the *Helping Children with Autism* package. John Howard said this package was just a beginning for people with autism. Labor also committed to implement the package and subsequently rolled it out through its 2007-2010 term of Government.

While I applaud the introduction of a program for young children with autism, I suggest the current scheme can be significantly improved.

The existing scheme funds very specific forms of early intervention; therapy delivered directly from Specified or Qualified Personnel. A scan of FaHCSIA's list shows panel providers cost \$120+ per hour, so the cost of 1000 hours of early intervention from these people exceeds \$120,000 ... so in FaHCSIA's existing model \$6,000 per year from the HCWA package provides under 5% of a child's early intervention need.

Many families who are eligible for HCWA early intervention funding say they cannot access the clinicians their child needs. FaHCSIA's panel model is impractical because the existing workforce is neither big enough nor trained to deliver the 5% of essential early intervention already funded through HCWA.

The research underpinning the Health Department's advice is based on more practical and cheaper delivery model. Instead of requiring clinicians to deliver therapy through face-to-face servicing with the child, researchers have their clinicians supervise delivery of therapy. The clinicians train and supervise students, childcare workers, aide staff, respite workers, family members and others (who may currently provide 20+ hours per week of relatively unstructured and unsupervised care and support for the child) to deliver a child's therapy.

Some people suggest that parents and families can be responsible for providing 20+ hours of therapy per week for a child with autism. This is simply not practical for most families. Many parents cannot find the required 20+ hours per week in their schedule, nor can they add such a load to the burden of working and caring for all their children. Children whose parents are not effective therapists miss out.

Further, there is a substantial risk that the family will be emotionally and/or mentally scarred or damaged if the therapy they provide does not deliver an optimal outcome for their child.

A child with autism may be in child care or attending pre-school. Their disability may require support from an “inclusion” support worker or teacher's aide. The existing services rely on childcare administrators and pre-school teachers (who have little or no clinical knowledge of autism) to supervise the child's support workers.

Governments could choose much better options. Government should encourage (or at least allow) clinicians who are responsible for a child's early intervention to train and supervise care and support workers to deliver individual therapy for a child with autism in a range of settings. Instead of offering just 5% of a child's need, this model offers substantial benefits from meeting most of a child's early intervention needs at little or no extra cost.

Labor needs to explain its election promise (see <http://www.alp.org.au/agenda/more---policies/a-better-start-for-children-with-disability/>) of \$12,000 of early intervention for children with a disability: how will Labor improve its service model and/or the workforce to deliver appropriate services for all the children with funds for early intervention? Will this dilute access to clinicians for children with autism spectrum disorders? Is the *Helping Children with Autism* package “just a beginning” — if so, what comes next — or is it all that Labor will provide?

The Liberals needs to explain which “almost 6,000 disabled children” will be eligible for up to \$20,000 each per year (see <http://liberal.org.au/Latest-News/2010/07/30/Real-action-to-help-students-with-a-disability.aspx>) and where the extra clinicians will come from to deliver services. This is a small fraction of children with severe or profound disability who need better outcomes from their education.

More generally, Australian governments need to improve awareness, training, services and workforce planning in their health systems for people with autism. The Australian Institute of Health and Welfare in its report on *The burden of disease and injury in Australia 2003* ranked autism spectrum disorders 2nd (following asthma) for boys aged 0-14 years, 8th for girls and 15th for men (the male to female ratio for autism diagnosis is 4:1). The number of people diagnosed with autism spectrum disorders has more than doubled since 2003 so the ranking of autism may have risen in the meantime. The significance of autism spectrum disorders is not reflected in planning, spending or staff training in the health sector.

Australia prides itself on its health system and its human rights record. But its so-called universal health system does not provide therapy and early intervention for children with a disability. Articles 23 & 24 of the United Nations Convention on the Rights of the Child (CRC) give children the right to treatment, rehabilitation and education. While Australian Governments pride themselves in having signed the CRC, and the UN Convention on the Rights of Persons with Disabilities, they refuse to actually comply with these conventions: they refuse to legislate the Right to essential treatment, rehabilitation and education services for Australian children. Australian politicians and bureaucrats insist on protecting their power over how much and which types of treatment, rehabilitation and education they will fund for a child with a disability.

I was surprised and alarmed to hear in recent discussions in the media that Australia's health system does not provide essential follow up therapy for children who get a cochlea implant. The public so-called universal health scheme and private health insurance both ignore crucial health services for children. Political agendas mean that Australia's health system denies our children the treatment and rehabilitation they need for a fair go in life. This is a national disgrace.

Schools exclude students with behavioural pathologies. Schools and students cannot access appropriate clinicians and services. As a result, many students with a disability do not get an effective education. This reduces their prospects for employment and/or independent living.

Because Australia's non-universal health and education systems are clearly failing people with disabilities, the disability sector is responding to the health sector's neglect and disregard for its responsibilities in early intervention — hoping to minimise demand for disability services, care and support. But politicians and finance bureaucrats do not sufficiently support these efforts to improve outcomes for people with a disability.

The election offerings for children with disabilities from both major parties are impractical. At best, they are incomplete. The political parties need credible policies for children with disabilities that commit to:

- ensuring children, especially those with a disability, have Rights under Australian law to treatment, rehabilitation and education;
- locate clinical services for early intervention, treatment and rehabilitation for children with a disability properly in the health system;
- develop a workforce of clinicians with the training and experience needed to deliver appropriate treatment and rehabilitation services for children with a disability;
- employ practical models for meeting the treatment and rehabilitation (early intervention) needs of children with a disability; and to
- improve education support and clinical services in school setting, including services for students with behavioural challenges and pathologies.