ATAC
Action for Tasmanian Autistic Children

18 March 2015

THREE EDITORIAL ARTICLES DISCUSSING THE NATIONAL DISABILITY INSURANCE SCHEME PUBLISHED IN THE ATAC NEWSLETTER IN JANUARY, FEBRUARY AND MARCH 2015

[PART 1 OF 3 in a series of articles on the NDIS]

THE FAILURE TO INTRODUCE EVIDENCE-BASED PRACTICE FOR AUTISM AND TO KEEP ABREAST OF SCIENTIFIC RESEARCH IS NOW COSTING AUSTRALIA VERY DEARLY

In the first few newsletters for this year I will be examining what is happening with the National Disability Insurance Scheme and analysing what the future holds for this scheme.

The first public meeting conducted by the Productivity Commission was held in Hobart 20 June ,2010. The scheme itself is not planned to be fully implemented until 2017.

ATAC gave the very first submission to the Productivity Commission and this submission stressed the need for early evidence-based interventions for children with autism. We pointed out that at the time of our submission autism numbers were doubling every five years. We stated that unless early-intervention was introduced, the life-time costs of caring for people with autism would bankrupt the scheme within a very short period.

It now seems very likely that the increase in the numbers of people with autism by the time the implementation of this scheme is completed, that it will provide little improvement in the position of those with disability.

Right from the beginning of the scheme the autism numbers were underestimated. A *Price-Waterhouse-Coopers* commissioned by the NDIS in 2011 stated " … every 7 hours an Australian child is born with an autism spectrum disorder." This amounts to 1,251 children being diagnosed with autism each year. In 2011 the **actual** number of children in Australia diagnosed with Autism Spectrum Disorders was **5,000.**

Reports from the trial sites initially showed no numbers of children with autism being reported. Later reports have placed autism at 35% of those signed up. This placed autism as the largest disability group for the first time passing those with intellectual disability who were on 31%. A recent report from South Australia placed autism at 40% of those signed up for the scheme. It seems clear that by 2017 the cost of looking after children with ASDs that the same shortages of services available will be the same as exists today, or more likely be worse!

By that date there will be at least 9,000 children per annum in Australia being diagnosed with autism. However, this is not the greatest problem that we face. As those being diagnosed age, and their families can no longer care for them, the cost of assisted living for them (Group Homes) will be unsustainable.

Since de-institutionalisation, all Australian States have provided services on a generic basis - ie one size fits all without regards to the specific needs of each Disability Group. This approach is being repeated by the NDIS. We have experienced Government-supplied services for the Disabled, private enterprise services, and now a mixture of the two, all based on this generic approach, regardless of the fact that it continually fails at enormous expense to the taxpayer. There is a substantial and expanding industry providing untrained carers to give respite services to families of those with Disabilities.

We are faced with a simple question today. Can the NDIS be resurrected, or are we heading to inevitable failure? What we have at present is a system for disability care which favours the service providers instead of providing the varying services that scientific evidence proves is necessary for those individual disabilities. **The model that is used by the NDIS is one that is designed to meet the needs of the 11% of physically disabled people.** ***With 89% of the disabled in Australia having brain-related disorders, we must cater for their needs, or the scheme is doomed to failure at an extremely high cost to the tax payer*.**

With autism and intellectual disability constituting between 60% and 70% of those with disabilities it is madness to ignore scientific research is telling us. It is time to abandon any programmes which are not based on scientific evidence. It is time to implement programmes that are evidence-based, and that will dramatically cut down costs as they are implemented and ***begin to work*.**

Many of the areas that required to implement the needed changes are under State Government control. Changes to the NDIS format will furthermore be needed.

For instance the latest research is showing that those with autism who achieve the optimum outcomes are those who commence evidence-based programmes before they are 2 years old. The only State Government in Australia who is implementing a policy to achieve this goal is the Tasmanian Government.

It is essential that changes to Early-Childhood programmes run by State Health authorities are changed in order to achieve this result. Training of staff for these programmes will be required. To bring about this change throughout Australia the NDIS should provide funding to help State Health systems to establish programmes to achieve this reform.

Early interventions need to be followed up by evidence-based programmes in schools. The NDIS should provide grants to State Education Departments to institute these programmes throughout Australia.
In countries such as the US where autism treatment is more advanced than it is in Australia, programmes are individually planned and implemented under the guidance of Board Certified Behavioural Analysts (BCBAs). Australia wide there are only 20 qualified BCBAs and no Australian university offers a course to qualify people as BCBAs. The NDIS should offer Australian universities incentives to introduce such courses.

States should be funded to provided courses to qualify BCBA assistants so that there is a trained workforce of teacher aides and service provider carers who can work in the approved programmes.

The choice is stark. On the one hand we can continue with a scheme based on repeating our past mistakes and ignoring scientific research and evidence-based practice. In so doing it must be understood that the greatest cost to the taxpayer comes parents can no longer care for their autistic children, and these children then have to go into assisted care, eg group homes. We need to understand that children born when the recent major increases in the rate of autism have occurred have not yet reached that point.

When this does occur - over the next ten years - the cost of caring for those with autism will shoot up dramatically. **TWENTY** YEARS OF FAILURE is enough. The ordinary taxpayer can no longer afford to keep afloat a system that has continuously failed and is based on the beliefs and prejudices of so-called experts who can provide no scientific evidence to back up their outmoded and ineffective ideas.

[PART 2 OF 3 in a series of articles on the NDIS]

NDIS IMPLEMENTATION IS TIED TO THE THINKING OF THE 1970s. AND IGNORES ALL SCIENTIFIC ADVANCES OVER THE LAST 30 YEARS.

The genesis for a National Disability Scheme was the Whitlam Government in the 1970s. It was not implemented at that time because of the dismissal of this government in 1975. At that time mental health and much of the disability sector was still confined to institutions. So the then-proposed NDIS would have been for those with physical disabilities only.

When the institutions were closed, no specialised services for those with mental health issues or brain disorders were provided by State Disability Services. These people were catered for by increasing respite services in order to give families a break from the care they provided. As the numbers of affected people at that time were quite small, it was considered that this is all that was necessary.

Since the 1970s, the point when a National Disability Scheme was first mooted, there has been a **fundamental change** in the composition of Disabilities within Australia. At that time, physical disability was by far the largest proportion of those who were disabled. Today physical disability comprises around **11%** of the Disability Sector, while the remaining **89%** is comprised of those with various disorders of the brain. Today were are still trying the make the vast majority of those with disability to fit into a scheme designed for and appropriate to a **small majority.**
The tragedy is that the cost of inappropriate services being provided to the majority of the disabled has now made it impossible for States to provide the services needed by those with physical disabilities. ***As a result, neither the physically disabled nor those with brain related disability are being adequately provided for by a scheme that was originally modelled on the needs of the physically disabled.***

Other countries who face the same crisis in Disability Care have taken a different approach to Australia. At a recent *Alliance for Research Progress* in the US, Thomas Insel, Director of the National Institute of Mental Health (NIMH) summed up the situation in that country. I quote from the report of that meeting

> "Dr Insel began his remarks by describing the public health burden of mental disorders in the US and globally. In the United States in 2010, neuro-psychiatric disorders (mood and behavioural disorders and neurological disorders) accounted for a greater percentage of years lost to illness, disability, or premature death - at 18.7% - than heart diseases, cancer, and all infectious diseases. Dr Insel said that chronic, non-communicable diseases will be to the 21st Century what infections diseases were to the 20th Century, and that brain disorders both neuro-developmental and neuro-degenerative diseases will be the most disabling and the most costly of these chronic diseases.
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> He went on to outline the new BRAIN initiative of President Obama. This initiative will accelerate the development and application of new technologies that will enable researchers to produce dynamic pictures of how individual brain cells and complex neuro-circuits interact at the speed of thought.
> Dr Insel assessed where we are in the process of transforming diagnostics, therapeutics, and the culture of science and recovery. For diagnostics he said the field needs to move away from thinking in terms of mental illness as behavioural disorders, to thinking about them as brain disorders, for the therapeutics from thinking about chemical imbalances to looking circuit dysfunction, and at circuit-tuning as a way to address conduction deficits of the brain, and transforming the culture of science, from the idea of owning data to sharing data, and from viewing patients as subjects of research to ensuring that patients are research partners.
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> He spoke of the challenges needed so that we can get to new diagnostics, new therapeutics, prevention, recovery and cure. "
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> Click here *Alliance for Research Progress - October 14, 2014 Meeting, Full Report*

There is also a European Brain Initiative and a Japanese Brain Initiative, and they are co-operating and sharing data. Clearly the approach of the NDIS is not in tune with what is going on with Disability Research in the rest of the world.
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When Thomas Insel talks of transforming diagnostics, he is referring to the NIMH's move away from the DSM diagnostic criteria which is symptom-based to the new Research Domain criteria (RDOC) which is based on biological (genetic) causes of mental disorders. Already we have seen successes from this change, for instance the RAISE programme for schizophrenia.

With the cost of genome-wide scans scans lowering every year (now under $1000) it is only a matter of time before the research, using new Supercomputer technology, is able to diagnose accurately at birth. **If we are not to be left behind in Australia, a great deal of retraining of medical personnel is going to be needed.**

HOW IS THE *NDIS* IMPACTING UPON AUTISM IN AUSTRALIA, AND WHAT IS THE APPROACH IN OTHER COUNTRIES?

Firstly, we must acknowledge the one area in which the NDIS has had a positive effect for autism. The NDIS sign-up rates are revealing for the first time that autism has surpassed intellectual disability as now constitutes **the largest group of those with disabilities in Australia.**

Every time there has been an announcement of an increase in autism number, the so-called autism experts deny there is a real increase asserting absurdly that it is simply better diagnosis or that we are diagnosing more high-functioning autism, or that it has been the result of a change from diagnosis of intellectual disability to one of autism.

On his website, Bob Buckley of A4 has been showing that all these theories fly in the face about the true facts of autism prevalence. Now the NDIS sign-up figures is acting as a prevalence study for disability in Australia. Clearly the NDIS, when estimating autism numbers, took into account these false theories. **They have now had to admit they underestimated the number of people in Australia with autism**. I would recommend that in future the NDIS consult with Bob, so that they may get a more correct estimate of autism numbers in this country.

There is some evidence that the rate of increase is declining. instead of the steady 20% rate of increase which has occurred over the last 15 years or so, it now appears to have declined to 17% per annum. However, even if it does decline to 15% over the next few years, by the time that the NDIS is scheduled to be completely operational there will have been a further 30% increase which the NDIS must calculate in its future planning. **Clearly the NDIS, should it retain its current form, will have the same budgetary problems as the present State schemes do.**

The old methods of one service model for all disabilities based on the requirements of those with physical disability is no longer viable. If Australia is to be able to cope with the present crisis in Disability Care, we must accept and work with the findings of the latest research.

Though those with autism constitute the largest disability group, the full effects of autism are still vastly underestimated. For instance, genomic research is showing that people with ASD share genetic traits with people with ADHD, Bipolar Disorder, Schizophrenia, and Clinical Depression. A team at the Cross Disorders Group at the Psychiatric Genome Consortium suggests that 5 mental disorders and illnesses have the same common inherited variations.

Click here *What is Autism? What Causes Autism? - Knowledge Centre, Medical News TODAY*

In addition, disability groups are defined by their primary diagnosis. The result is that many people with Down's Syndrome, Cerebral Palsy, Epilepsy, Eating Disorders, who also have autism, are not grouped under autism, but under their primary diagnosis.

It is clear from the size the autism group within Disabilities, its association with other brain disorders, its many co-morbidities, and its continuing rate of increase that it is the major problem facing the Disability Sector. It should by now be clear that the present NDIS Scheme fails to take this into account, and cannot resolve any of the difficulties facing the sector. Unless radically reformed, the NDIS will constitute an economic catastrophe for the taxpayer as well as failing to alleviate the crisis in Disability Care in Australia.

Further Reading:

1. Unacceptable political games over early intervention for children with disability, Autism Aspergers Advocacy Australia

2 NDIS funding model 'fails autistic children' The Australian, November 22, 2014

3 Flawed NDIA approach implicitly blames parents for autism Autism Aspergers Advocacy Australia

4 NDIS funding: Cry of blackmail at move to slash welfare The SMH, January 3, 2015

5 Government running costs to reach record high as disability expenses mount' The Age, January 3, 2015

6 NDIA Annual Report 2013-2014 overselling itself,' Autism Aspergers Advocacy Australia, 30 November, 2014

7 Budget pressures hang over national disability scheme The Mercury, 7 December, 2014

8 Open letter on people living with autism, and request to meet Autism Aspergers Advocacy Australia

In the third article of this series, I will address how we can alter the NDIS in a way that will make it an effective scheme that tackles the main problems that have to this point been avoided.

Third and final article on the NDIS, IN WHICH we discuss whether the scheme can be salvaged, enabling it to make a real contribution to resolving the crisis in disability care.]

CAN THE NDIS BECOME PART OF THE ANSWER TO RESOLVING THE CRISIS IN DISABILITY CARE BY CHANGING THE FAILED METHODS OF THE PAST?

Our previous articles set out to conclusively demonstrate that the NDIS in its present form will become an economic disaster, failing to provide the services required to meet the needs of those with disabilities in Australia.

However, it is NOT enough to point out the obvious problems with the NDIS. In exposing the clear weaknesses of the present scheme, we need to present alternatives to make the NDIS work, both for the disabled members of our community and for the taxpayers who fund it.

There are distinct advantages to both by having a national approach. However, it must be one that co-ordinates and works with State Health and Education Services. If it does not, it will necessarily fail.

Already we are missing a great opportunity in the initial sign up to the NDIS. There is a real need for an accurate count of the numbers of people in the various categories of disability so that future planning can take place. **It beggars belief that**

this is not being done as part of the process of signing up to the NDIS. It is essential that this information is collated into a register of families to allow for future effective planning to take place.

Families in Australia should be asked if they are prepared to participate in research into their respective disabilities: this would become a vital tool in research on all disabilities, but particularly on those with brain disorders. The present position of those with brain disorders is that world-wide, researchers are seeking large numbers of people prepared to participate in relevant research. International collaboration is necessary to obtain those large research pools, so that we can advance our knowledge of specific brain disorders, and their causes. If such a register was kept in Australia, it would lead to an enormous increase in our own research industry, and make Australian researchers a target for being included in international collaboration. **This must be done if we are to become part of the international research effort, and therefor vastly increase our own research industry and the benefits that flow from such research.**

The USA leads the world in investment in seeking out an understanding of autism and of those interventions which can bring lasting improvement to the lives of those who are autistic. One million children are being born in the US every year with an autism spectrum disorder (ASD) and it is easy to understand why successive American Presidents have invested in research aiming to understand and find treatments for autism and other brain disorders.

The US is the only country that has a National Standards Committee that tests and researches the effectiveness of interventions for autism. To date, the only effective interventions found are various behavioural interventions based on Applied Behavioural Analysis (ABA). State by state grass roots campaigns have achieved State Legislation that requires Health Insurers to cover ABA, Speech Pathology etc for those with autism. In the remaining handful of State Legislatures, legislation is before the State Houses to bring them into line with the vast majority of states. Many states have renewed their legislation in order to increase services for those with autism.

These programmes are very expensive, with some states providing up to (US) $120,000 per annum per child. T**he reason for this is, as we now know, that diagnosis occurs too late.** Research has shown that autism begins in the second trimester of a pregnancy. A great deal of effort is now going into research in order that diagnosis occurs at birth. The latest research in this area from the USA now indicates that interventions should occur as soon as a child misses a developmental guideline. As soon as this happens, the mother is trained in the intervention. She receives further support from the team which trains her who visit her every fortnight and update the programme for the affected child. This means that **problems are addressed as soon as they arise, and not left until they are intractable and require extensive, and expensive, interventions.**

In Australia, we have a system of Child Health Nurses who are trained to recognise when a child misses a developmental guideline. All we need is to change the current approach which says 'wait and see if they catch up as they age' and replace it with a system of **immediate intervention.** By developing a group of trained specialist nurses, we can ensure mothers themselves are trained to carry out the needed interventions at a minimal cost. **The NDIS should fund states for the cost of training Child Health Nurses to make this possible.**

The advantage of using this method of intervention is that it is applicable to both those with autism and those with intellectual disability. It would be expected that one third of the children will not go on to develop autism or intellectual disability, one third will need further intervention, and there will be one third who will improve but who are so seriously affected that medical interventions will be needed. **The advantage of introducing such a programme is that it treats the two largest disability groups - autism and intellectual disability - who comprise two thirds of all disabilities. For a modest outlay when the first signs emerge we can dramatically reduced on-going costs over the long term, which at present amount to billions of dollars.**

For that group of children who need further interventions to enable them to be employed and live with minimal assistance, we will need more intense intervention programmes. This will require properly Applied Behavioural Analysts.

At the moment, Australia has only about 20 fully qualified Board Certified Behavioural Analysts. The NDIS should be encouraging and helping with the costs of introducing courses in Australian universities which will provide full training as occurs in the US. In this way we will ensure we have enough properly trained analysts to guarantee the success of interventions.

If this is done, we will ensure that this group of children will achieve good educational results, and so allow them to obtain future employment. They will then not be dependent on social welfare, as is now the case. This will constitute another immense saving to the Australia taxpayer.

What we next need to consider is how education systems in this country have failed children with brain disorders. In every state, parents are withdrawing their children from school and choosing to home educated them. The various State Education Authorities, alarmed at the loss of income, are responding by introducing new regulations that make it more difficult to home educate.

Not one Australian State Education Authority has chosen to implement interventions that the US National Standards Committee have tested and have found highly effective.

The only exception to this is the recently elected Tasmanian Liberal Government. This government is introducing the prize-winning ***Rethink Autism Programme*** in second term this year. This is an Internet based programme from the US which has many of the world's leading experts in autism interventions drawing up its interventions. This organisation through its Internet programme trains teachers, teacher aides and parents in how to educate children with brain disorders.

The Federal Government through the NDIS should support and help finance this initiative by Tasmania, and when it proves successful in Tasmania, should consider introducing in other states. The ***Rethink*** programme is designed for areas where there is little expertise in evidence-based interventions, both within the US and throughout the world.

By adopting this approach, and therefore by providing an educational service which has proven highly effective, State Education Authorities will encourage parents to return to main-stream educational services.

Every year that governments in Australia put off making the necessary reforms costs Australians dearly.

THE EFFECTS OF ADOPTING THE POLICIES OUTLINED IN THIS ARTICLE SO FAR

Autism is a very wide spectrum of disorders, with different degrees of severity. Approximately one third of people with autism are relatively high functioning. Another one third are more seriously affected, and the last third are very seriously affected with serious co-morbidities, such as epilepsy and other rare genetic disorders.

Those in the first group, with interventions commencing in the first year, should be able to function as well as any other child well before school age, and go on to higher education. Those in the middle group should be able function and learn at school so that they can gain qualifications and therefore employment, and live their lives without the need for support.

Contrast the approach I have outlined with the present approach of the NDIS. On the one hand, we use evidence-based interventions to reduce the number of people who will need care for their whole lives. The approach of the NDIS builds services designed to look after people for their whole lives. The approach I have outlined will, in direct contrast, reduce the cost of Disability Care into the future.

The present approach of the NDIS will become completely unaffordable as the increased numbers age and reach the stage where parents become unable to care for the children, and long term care in group homes becomes necessary.

The approach I have outlined will dramatically improve the lives of those people with brain disorders.

POLICIES TO ASSIST THE MOST SEVERELY AFFECTED GROUP OF PEOPLE SUFFERING FROM BRAIN DISORDERS.

In this group, many autistic people will be non-verbal, many will have uncontrolled epilepsy, and many will have other serious co-morbidities, and at times a combination of all the above. This is the group that the research industry is focusing on in their search to find the brain dysfunctions that cause these problems.

It is now just 14 years since the Human Genome Project revealed that there are about 20,500 human genes. Since our last edition, the following developments in research have occurred. In February this year the first comprehensive maps and analysis of the epigenome - the genes that don't produce proteins previously thought to be 'junk DNA', but now known to regulate the process of switching on and off genes - was published as an open access resource. Language delay has been linked to a chromosome deletion, and seven genes for X-linked disability, the most common cause of autism, have been identified.

With the advent of the Research Domain Criteria (RDOC), and the abandonment by the research industry of the DSM criteria, research is now focused on determining the underlying biological causes of brain disorders. The next phase will concentrate on finding ways to repair the mutated genes, and the circuits they affect. This could entail stem cell therapy, gene therapy, drug therapy, or a combination of these approaches. This will mean that in the future, as a result of continuing research the the development of methods to combat the effects of mutations and faulty circuitry, even the most severely affected will be able to live relatively normal lives.

The above facts are the reason for my criticism of the failure of NDIS to build a register of brain disorders occurring in Australia. Building such a register would be a magnet for international researchers, and the small but growing research industry in Australia would grow exponentially as a result of this.

In this third group - those most seriously affected by autism - there are a number of children who have very rare mutations that cause serious health problems. There is a very large cost attached to the provision of health care for this growing group of children who have need of continual hospital visits, visits to the doctor and specialist treatments. For example, every hospital bed day they take up costs the taxpayer $900.

The European Union, has a programme to test for rare disorders at birth. This allows for proper care plans to be drawn up, allows for research into these rare conditions, and allows for treating doctors to access up to date research and treatments for these rare disorders. The British National Health Service has recently added extra rare conditions to their testing programme.

Australia should consider a similar scheme which could lead to finding cures through international co-operation on these rare disorders.

In most states in the US there are laws that extend school age for the disabled until they reach 21 years of age. This allows those who are still progressing to continue their education with the school system, and move into higher education or alternatively gain employment. There is a considerable success rate for these people when they enter higher educational institutions, such as college and university. This is something that a national scheme could help finance in Australia.

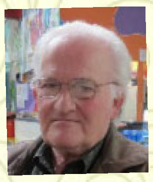
To sum up, in 2010 when the Federal Government asked the Productivity Commission to ascertain whether a National Disability Scheme was affordable, it was because it was understood that States could no longer afford workable schemes without national support. Only the FederalGovt. could afford to provide the required services. There was no investigation into whether those services being provided were appropriate, nor was there an investigation into the composition of disabilities within Australia, and the assumption was that the type of services being provided were adequate if only enough money was made available. Those few voices (*ATAC* and *A4*) who raised these issued were drowned out by the overwhelming voices of those who desperately needed extra services.

In the five years since the inquiry, the NDIS has been formed, and has commenced the present trials occurring in every State in Australia. **In the same period, there has been a considerable growth of the disability sector in Australia, and in the make-up of this sector. Autism has surpassed intellectual disability as the largest disability group. Combined, these two groups comprise two thirds of all those with disabilities in this country, and at the same time autism numbers are still growing.** Along with acquired brain injuries and other brain disorders they now comprise **89%** of disabilities within Australia.

In this final article on the NDIS I have put forward an alternative approach for a national scheme. This approach brings Australia into line with the international research programmes to solve the problems created by brain disorders.

I will finish this article by reminding you that in Tasmania, we have clinics attached to the three major regional hospitals that treat those with cancer. We have diabetic clinics in each region, and dialysis units in each region. Yet for autism, **which affects more people than all of these conditions *combined*, and which costs the taxpayer more than all three of these there is no service attached to any hospital in Tasmania which treats people for autism.**

Furthermore, by adopting these proposals, we would transform the entire nature of this group of people with brain disorders. From a group which is at the moment a major drain on the taxpayer, they would become a group that is enabled to contribute to the Australian economy as they also dramatically change the quality of their lives.



Roger Law - Secretary ATAC

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