

**Greg Mahony**

**Submission to the Inquiry into Disability Care and  
Support**

## **Perspective of Parent and Economist**

I write as a parent of a child with autism and as an academic economist. I believe that the scope of this Productivity Commission Inquiry, while admirable, is far too ambitious to lead to any comprehensive national scheme for Disability Care and Support that is likely to be implemented by government. I wish this was not so, but I fear the inquiry process itself might be raising false hopes among disabled people and carers. At the same time it could generate fruitless quests for schemes or processes to address a vast range of pressing and valid concerns. I appreciate that the terms of reference invite detailed analysis of every conceivable issue but the Commissioners might pause to reflect on how they can best serve the disabled and carers. The funding issue is best dealt with by the Treasury in the context of the Henry Review of Taxation. The Inquiry should limit itself to calculating the cost of a reasonable scheme and other scenarios then advise Treasury. To do work on the efficacy of several funding arrangements is replicating effort. It is blatantly clear that the opportunity for any scheme with a large insurance component is strictly limited by the lack of income of most disabled people (save perhaps the cases of acquired injuries that win compensation) and the severe constraints that living with disability puts on them and their families and carers. There is precious little opportunity to engage in assurance – as saving is thus constrained – so inter-temporal substitution of consumption is near impossible. Insurance principles are violated for existing cases of birth related disability unless the population can be persuaded to insure against this contingency. Even if this was achieved existing cohorts of people with disabilities would need to be funded from fiscal transfers for most of their lifetimes.

## **The Inquiry Process**

My view is that the expertise of the Productivity Commission, which lies in economics and the social sciences, is best suited to investigating and recommending broad pathways for reform that should be adopted. In this submission I suggest the limited areas in which the Inquiry might make recommendations. The very nature of my market oriented recommendations precludes the necessity for detailed prescription about the types of services and the exact manner and timing of their delivery. It is in fact such over-prescription by a plethora of agencies that is symptomatic of the current parlous state of the `system`.

I note the Inquiry's early notices and the Issues Paper says it invites submissions but it wants people to focus on how to build a good system as everyone agrees that the current `system` is bad (p.4). This appeal seems misguided. As evidenced by the submissions to date it is only by enumerating the failings, injustices, and inequities of the current `system` that the case for reform can be made. Looking at a sample of the written and verbal (public) submissions, the clear impression is that the

Commissioners are now dealing with a range of needs - physical, material and emotional that is most difficult to digest let alone use to prescribe specific policy solutions. The Inquiry invites opinion on the 'nitty gritty' and there is plenty of it. In the wealth of detailed and heart rending concerns, a clear picture of poor funding, neglect of many aspects of the human rights of the disabled and carers as well as grossly inadequate support and access emerges. Reading the submissions one almost recoils at the debilitating struggles by disabled people and carers to cope with daily life and plan for their futures. There is also much wisdom evident in the submissions. Wisdom that points to an overhaul that provides the maximum autonomy and choice to the real experts in each case – the disabled and their families or carers. It is of grave concern that to date no state agencies or government departments appear to have offered a rationale or defence of the current state of affairs.

As an academic I am concerned that the methodology adopted for the Inquiry sees the Commissioners addressing too many questions rather than proceeding in a more systematic manner. Every effort should be made to address two big sets of questions separately. The first set is related to the funding and expenditure regime for a national scheme, and the second on how particular services should be delivered and paid for. This is a concise outline of the policy challenge facing this Inquiry. I feel that for an Inquiry of the Commission it is best to focus on these two sets of questions and provide a framework within which specific solutions can be worked out at the state, local and most emphatically individual and family level. Solutions are probably specific to each disability group and likely vary between states, localities and income groups.

### **Economics as a Guide**

The Inquiry states its intention to use cost benefit analysis so I was pleased to see Commissioner Scott's discussion of this in the ACT in July 2010 during Bob Buckley's most informative submission. She outlined the logic of relating the cost of early intervention for ASD to the (appropriately discounted) long term benefits of reduced care needs of the child and future benefits of improved self support and even income earning capacity in his or her adult life. This approach is commendable. I urge the Inquiry to commission research on such questions across a range of disabilities. Doing social cost benefit analyses for several representative groups of disabilities would illustrate neatly the monetary impacts on families and the extent of the challenge to allow the disabled to care for themselves or be cared for. A back of the envelope cost benefit analysis of our family situation indicates that if we were to provide Sammy with the level of care that we consider 'average' rather than ideal for the rest of his expected life, even with existing levels of state subsidies, it equates to liquidation of all our net worth over time and still we face significant

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amounts of our lives spent caring for him. If we were allocated funds directly that are currently expended directly and indirectly on our son we believe we could provide moderately well for him. My guesstimate of the efficiency dividend of such a change is in the order of 30-40%. Furthermore quality of life for our son and his family would improve immediately and dramatically.

Numbers on current expenditures and orders of magnitude regarding potential costs of alternative schemes are crucial to coming to grips with the complexity of the issues that the Inquiry is tasked to investigate. I trust the Commissioners are working towards a set of such numbers. I feel these data need to be available at an early stage so as to improve the chance of parties finding common ground. Most of us engaged in one area of disability have little idea of the magnitude of issues, costs and funding outside of their specialist interest. Without such data how can one appraise recommendations related to any national scheme?

### **Let the Market Deliver Services and the State Income**

Many of the submissions from the disabled and carers support an individual funding model where agreed amounts are deposited in designated bank accounts. The instincts and wisdom of these submissions gels well with economic theory. It is usually argued that consumers are the best judges of the pattern of consumption which suit them best, from any given level of income. In the jargon of economists it 'maximises their welfare subject to an income constraint'. The needs of each autistic child are intrinsically specific to that person, given the nature of Autism *Spectrum* Disorder. Yet state agencies obstinately purport to deliver a menu of services over which this consumer and his guardians have little control. There is a grossly inefficient veneer of inadequately trained people making decisions on his behalf. Or most often ignoring his needs and over-riding his human rights until parents shout loud and often. We deal with over 30 agencies related to Sammy's disability, his education and therapies. The transactions cost for us and the agencies are very significant. Many families are deterred from accessing services for this reason. The efficiency losses are large, real and constant. The acute stress on all concerned is a consistent theme from families living with autism. This externality from bureaucratic inefficiency and high handedness imposes significant physic and other social costs on all concerned.

Economic theory points to the preferred option here – the individual funding model. Such theory also highlights the role of market failures, asymmetry of information and questions of endowments and income distribution. I am sure the Productivity Commission has the capacity to couch its report in these terms to conclude that the individual funding model has overwhelming merit. How can I be so sure?

The existing system clearly cannot be 'fixed'. I would need to see good arguments why any of it should be maintained. Some elements might well survive but in transformed guises. For example

non- governmental respite agencies that may receive block funding for training and quality control (to address market failure) but otherwise supply services in the market or least a quasi-market. I would also like to see much greater consumer representation in such agencies as part of any registration procedure. As the market is a `good servant but a bad master' it needs appropriate and sensitive regulation of standards and ethics of such agencies. This can only be achieved in such a complex area as disability by the empowerment of consumers in the regulatory process.

With the bulk of funding in the hands of consumers markets could be developed to deliver a diverse range of care needs. It was said in defence of the coordination capacity of markets to deliver diversity and quality that `Paris is fed'. While the state would need to address market failure issues in areas such as training and education, and support advocacy for some groups these issues should be expected in a market were externalities, spill-over effects, uncertainty and asymmetric information abound.

The basic message is clear: the disabled and their families know what is best for them so let them negotiate it in markets to the greatest extent that is feasible. We will only know the limits to what is feasible by experience. Access to, and control of, income is the obvious constraint on any experiment to implement a new scheme based on individual funding. The scheme should support those who need assistance and facilitation in negotiation and making arrangements for market delivered services. The scheme should allow a range of community advisors to offer services on a fee for service basis or non government agencies could receive bulk funding and be monitored by consumer groups. This is one of the many areas that not for profit bodies appear to have a comparative advantage in the delivery of services.

If it has not done so I trust this Inquiry commissions a range of academic work focused on the circumstances of specific disability groups. The Inquiry could be swamped in discussions of the particulars of service delivery, competing models, governance and auditing issues. The complexity of issues, the anger and frustration of clients along with the inability or incompetence of agencies, as reported by the public submissions can make it all appear to be a so-called `wicked problem'. Clearly care and support for the disabled is a complicated issue and will require a range of complex solutions but the analysis should not be overwhelmed with detail.

### **Implementation – a Trial of Individual Funding**

The current public sector reform debate talks of citizenship and service delivery. Disability Care and Support could be seen as an area for a promising trial or test case of the government's commitment to these ideas. It seems an ideal area as no fair minded person doubts the real needs of the disabled; although there will be little agreement on what should and can affordably be done. For the trial existing levels of expenditures could be estimated and transformed into individualised accounts.

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Invite clients and carers to opt in or out, and be subject to a process of approval for the trial. The probity of such a trial of individual funding is underpinned by the fact that families have an honest and caring commitment; and are renowned for the long hours of hard work associated with the role. Unlike disparate bureaucrats who do not read clients' files these individuals and families are experts regarding their own circumstance – they have thought about it every night. The non-government agencies and volunteer groups associated with every disability group offer a unique chance for co-production – another fashionable concept that could be part of the trial. Trials could start in one or two jurisdictions or areas e.g. Tasmania or the ACT. A system of vouchers for areas such as education might also be considered as part of the trial if full autonomy for the consumer is too daunting. Anxiety about auditing should be assessed against the appalling waste and inhumanity of the current regime.

I appreciate the public hearings have already been held in the ACT but I would be most willing to discuss my submission with the Inquiry at any time.

### **Background of Author**

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Our 10 year old son Sammy, has moderate to severe autism and an intellectual disability. He is largely non verbal and incontinent at night. He is also very social person, perhaps atypically so, and very fun loving. Nevertheless, the impact of Sammy's disability on my family has been profound both financially and in our individual capacities to thrive. My wife who is a trained, Diploma level preschool teacher from the UK took a 9 year break from her university studies due to Sammy's needs. She has now returned to university and hopes to graduate next year. I am older than my wife and so face retirement to take on a fulltime carer role for as long as I am able, while my wife returns to work. My superannuation is less than it might be due to a late start to my academic career. Sammy enjoys the gift of a loving and tolerant 14 year old sister, Ingrid, who he adores; he calls her 'my ee'.