Real Support for Autism

Submission to the Productivity Commission's Inquiry into the Long-Term Care and Support of People with a disability

Sydney Hills Autism Support Network

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SUMMARY OF KEY POINTS

- **The concept of a new scheme for the long-term care of people with a disability is welcomed and supported.**

- **There is a need to create a National Basic Standard of Care for autism that assists in developing Individual Care Plans at the point of diagnosis - reviewed annually to ensure appropriate services are delivered.**

- **There is a need to establish a centralised autism database to fully understand the scope of the problem in Australia, and one centralised agency to oversee the life-long care of individuals with autism.**

- **ALL children with autism must receive intensive early intervention before they begin school to maximise their potential.**

- **The school setting should be expanded to include the delivery of therapy services according to individual needs. After-school care is needed to support working families.**

- **Extreme behaviour issues should be immediately addressed with an 'Autism Super-Nanny' intensive behaviour intervention approach until the problem is resolved.**

- **Develop a centralised patient information database so medical information can be accessed by a number of health professionals and service providers.**

- **Life-long learning options should continue after school ends for people with all levels of ability – for example expanding TAFE services to include a TAFE LIFE SKILLS program.**

- **Respite care for carers should be truly flexible to meet individual needs – rather than the current one-size-fits-all approach.**

- **Ongoing research into the causes and treatments of autism must be supported.**

Introduction

The Sydney Hills Autism Support Network thanks the Productivity Commission for its inquiry into the long-term care and support for people with a disability.

Living with a family member who has autism is a profoundly challenging experience for both the autistic person and every member of the family.

While schools and health care services ‘do what they can’ with limited resources, it is clear that a comprehensive long-term plan is needed for each individual with autism not only to provide critical care and appropriate education, but to reassure families that their family member has a care plan into the future.

The Network would like to address the key questions set out in the issues paper – from an autism perspective.

Key Questions

Who should be in the new scheme and how could they be practically and reliably identified?

The Sydney Hills Autism Support Network supports the inclusion of all people with Autism Spectrum Disorder in the new scheme.

Autism is generally diagnosed by a paediatric specialist in the early years of life, or by the school system – however, establishing a centralised autism database would assist in the identification of people with autism.

Which groups are most in need of additional support and help?

All people with autism need additional assistance throughout their life, however it is those people with autism who **never acquire language** and display severely challenging behaviours - and their carers - who will need life-long assistance.

Similarly, children in the first five years of life who are diagnosed with autism **must be prioritised** and provided with intensive early intervention – at least 20 hours per week – as research shows this leads to the best outcomes later in life.

What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

A system that provides early identification of people with autism and an Individual Care Plan following diagnosis, with **annual reviews**, would ensure all people with autism receive a level of support that meets their needs.

How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

The needs of people with autism change according to their age and stage of life. Annual reviews of Individual Care Plans would identify gaps in service provision, or changes according to need.

Currently services are provided and taken away annually according to the ‘flavour’ of disability funding that year and appeals are often disregarded or heard by the service provider with an outcome already in mind.

A better model would be to establish a NATIONAL BASIC MODEL OF CARE and an ANNUAL BOARD OF REVIEW approach for every person with autism.

An independent panel of review, unrelated to service providers or government agency overseeing service provision, would create a fairer appeals process.

How should the amount of financial support and service entitlements of people be decided (and by whom)?

“Autism is an expensive hobby”. Significant medical, educational, pharmaceutical, dietary and therapeutic expenses are incurred when a family has a member with autism.

While continuing to receive basic health care, respite care and educational services, families with a child with autism could be granted tax-exempt status, allowing the provision of very specific care services for their child as long as documentation and receipts showing spending on appropriate items was provided.

What kinds of services particularly need to be increased or created?

The Sydney Hills Autism Support Network recommends the following types of services be considered:

Improved diagnostic services

The current way of diagnosing children with autism is ad hoc and many children slip through the diagnostic net – missing out on critical early intervention. Better education of health professionals is needed to ensure children are diagnosed and treated appropriately, as well as improved preschool and school screening.

Individualised Care Plans

There is no such thing as a basic standard of care for a person with autism. Currently, there is very little (if any) follow up of people with autism following diagnosis unless families demand it. It is possible for a child to receive no early intervention or other services following an autism diagnosis. In an ideal system, a national basic standard of care would inform an individual care plan, tailored to suit the needs of the child and the severity of the disorder, at the point of diagnosis and would be reviewed annually by a panel of child behaviour and therapy specialists. This would feed into and inform the child’s school IEP program. Counselling services for families could form part of these care plans.

After school care

Extremely limited after-school care options exist for children with disabilities, and almost none at all for those with severe or profound disabilities. Given the excessive cost of raising a disabled child, after school care options must be made available to support working families.

A variety of school options

A variety of educational options from autism-specific schools and supported classes in mainstream schools through to residential and special schools are essential to address the diverse types of autism. Residential schools like Kingsdene at Carlingford NSW should be supported, not closed, as sometimes families can continue to include the child with a disability as a family member if they have a weekly residential school option.

Post-school options – life long learning

Some people with autism – particularly those who are non-verbal - will never be able to enter the work force, even in supported employment. Currently only limited post-school options exist. In a good scheme, post school options for these people would include meaningful activities and the opportunity for ongoing life-long learning and life skills training.

Extend the therapy grant to all school aged children

The introduction of funding for children up to the age of six is welcome. However, therapy needs to continue when a child enters school. Extending funding to all school aged children would enable schools and parents to access specific therapies for each child based on their needs.

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

- Establish one centralised agency overseeing and co-ordinating all aspects of the autistic person's lifelong care – like the UK Council model.
- Extend the community nursing service (baby health clinics) to maintain records and provide referral service to children with disabilities beyond babyhood.
- Create a centralised data base of information.
- All service providers should be able to access a centralise database of patient information to avoid multiple filling out of forms.
- Expand the school system to provide additional therapies according to need.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

When first diagnosed, The Sydney Hills Autism Support Network supports the provision of a minimum of 20 hours per week of early intervention for children with autism – preferably using research-based intensive behavioural therapy – to optimise the child's potential in the early years. This could be funded through tax exemption for families to self-fund a tailored program.

For challenging behaviours, immediate provision of behavioural assessment and intervention programs before that behaviour becomes learned is recommended.

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

The Sydney Hills Autism Support Network recommends a program of life-long learning – beyond school years – be implemented to maximise participation or enhance life skills. This could be provided by adapting or creating new programs to be delivered through the existing TAFE system (TAFE LIFE SKILLS).

How can a new system ensure that any good aspects of current approaches are preserved?

A review of current approaches – including parent and client surveys and collection of data from service providers – would identify the most effective and efficient services.

Consult clients and parents/care givers about what works, and expand on those services.

What should be done in rural and remote areas where it is harder to get services?

The use of technology – ie SKYPE or internet conferencing would assist by providing virtual therapists to remote areas.

Providing supported accommodation – like Ronald McDonald House – attached to hospitals while families attended an annual board of review for the creation of – or review of - Individualised Care Plans would be ideal.

How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

Develop a patient information database

People with autism need an integrated therapy approach – often seeing multiple specialists, doctors and therapists to address the complex disorder. Centralising patient information and details would lead to a more streamlined approach to management, and avoid duplication of files and the need for care givers to provide the same information many times to many different people.

Create a National basic standard of care

Currently, a basic standard of care for children with autism does not exist. Issues are dealt with on an individual 'ad hoc' basis, as they arise – often by health professionals with very little knowledge of the disorder. Developing a National Basic Standard of Care for Autism would ensure each newly diagnosed child would receive access to essential services, and allow GPs and Paediatricians to follow accepted care and therapy guidelines – and track progress across various therapies.

How should a new scheme be financed? How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

The Sydney Hills Autism Support Network supports the concept of a small increase in the Medicare levy to finance a new comprehensive scheme for life-time care of people with disabilities.

Families who have a child with a disability could be granted **exemption from tax** to fund the excessive costs of raising a disabled child.

What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?

"Disability can happen to anyone at any time". Any national disability insurance scheme should provide compensation on a no-fault basis. It must have buy-in for all people to acknowledge the indiscriminate nature of disability.

Other ideas for a good scheme

Establish a list of nationally recognised therapies for autism

This will assist parents and health professionals to create an effective program with recognised therapists.

Solve problems quickly – the Autism ‘Super-Nanny’ approach

Serious problems often arise in autism that are over and above ‘typical’ behaviour. Anger, obsessive behaviours or aggression may have a sudden onset – often the result of inability to communicate. Families often need an intensive burst of help to understand and treat these behaviours before they become ingrained. Under the current system, the specialist treatment may take months to become available. A better way of managing these problems could be an Autism Super-Nanny approach where a behaviour specialist ‘lives-in’ for a period of time to fully understand the problem and offer on the spot and long-term solutions. Another option would be to offer a teamporary ‘live-in’ therapeutic assessment centre where families can be observed and treatment evaluated quickly, rather than the current hit and miss approach of making appointments over an extended time.

Support autism research

Better research is needed into autism in Australia, and better understanding of international research would benefit Australian people with autism. Currently, diseases like cancer attract the lions share of research dollars – a percentage of a National Insurance Scheme for Disabilities could be channelled into disability research, particularly those fields that are under-represented.

Reduce the waiting times

Unacceptable waiting times exist to access services for people with autism, increasing stress on families, particularly at the point of diagnosis.

Conclusion

Autism can impact any family from any background at any time. It is a disability that involves extreme behaviour issues as well as extreme learning difficulties. Currently, parents must fight to access even basic services for their child, and constantly ‘prove’ their child’s needs.

The Sydney Hills Autism Support Network welcomes the Inquiry’s review of the way services are provided – and thanks the Inquiry for the opportunity to have a say about the possibility of ‘real support for autism’.