A4 Autism Aspergers Advocacy Australia

Submission on

The Integrated Plan for Carer Support Services

16th December 2016

The *Integrated Plan for Carer Support Services* (the Plan) seems to fall well short of needs.

In a quick review (conducted December 2016), the Carer Gateway (see http://www.carergateway.gov.au/) was unhelpful. In particular, it lacked sensitivity to location and disability type(s).

There are questions about efforts to meet the needs of carers through online services. Reports suggest 47% of Australians, almost half the country is functionally illiterate. It is likely that the rate of illiteracy is much higher among carers. So, an online gateway cannot help many of the carers who most need information.

The first stage of The Plan needs much more work … and has yet to recognise and address the issue of elevated rates of functional illiteracy among carers.

In relation to the second stage of The Plan, governments are making strong moves away from supports for specific disability types. Governments prefer generic disability supports or, even better, supports for people with disability from mainstream services.

But carers often tell *Autism Aspergers Advocacy Australia* (known as A4) that providers of generic disability information and services simply do not understand the needs of autistic people and their carers. Carers are frustrated by the waste of time and effort trying to deal with people and systems that do not understand, and usually refuse to recognise, the distinct nature of *autism spectrum disorder* (ASD), and the consequent needs for distinct services and supports.

A key area of need for autistic people and their carers is the issue of behaviour support (see Behavioural needs of autistic Australians must be met) yet governments refuse to recognise and address this crucial issue.

Governments refuse to listen to carers about the abysmal outcomes for autistic people in education and employment.

The NDIS aims to dump as much support for autistic people as possible on "informal supports" (which means carers).

The Plan talks about increasing uptake of services … but the relevance of services on offer for carers of autistic people (where many of the carers are autistic or neurodivergent themselves) is minimal and marginal in most cases. Any uptake of largely irrelevant services will be short-lived and uneconomic.

For example, individual advocacy for autistic people and their carers is experiencing chronic under-supply. This is an essential service … but it is omitted from The Plan. Carers quickly give up trying to access these services when the service offered and/or provided does not meet their needs.

The Plan has seen the demise of *Autism Asperger ACT* … and other groups like this are struggling to continue.

The Plan seems to be all image and no substance. There are fancy presentations about a Service Delivery Model … but few if any actual services. The "service model" requires "governance" but there is little if anything to actually govern. It has categories to group services into, but where are the services to be grouped into all those categories? Are there even resources to support services?

For example, the document seems to indicate that emergency respite (which really means support in an emergency – note: respite is a dirty word in the NDIS so we are all being trained to not use it) … yet, the Gateway seems to suggest that I call 000 – which I doubt would work.

Please contact *Autism Aspergers Advocacy Australia* if you would like any more detail or further explanation.