**Comments on NDIS Home and Living Policy**

**SDA**

In the consultation paper, “An Ordinary Life at Home”, it seems that it is assumed SDA will continue in more or less its current form.

We would argue that in its current form, SDA is not meeting the needs of participants in important areas, and in particular is not meeting the needs of families trying to provide accommodation for participants who are family members.

We are the parents of a young woman with severe autism and intellectual disability, who is given to frequent episodes of distress and challenging behaviour, and requires high intensity 24/7 support. Because of the absence of appropriate accommodation in the rural area of northern Tasmania where we live, a family member helped us to fund a house purpose-built for her. After going through an extremely lengthy, stressful and opaque process in applying for our daughter to be assessed as needing SDA, our application was initially rejected, but eventually approved after we pursued the case further. We were then able to have the house that we had built for our daughter enrolled as an SDA dwelling, and finally started receiving payments which made our investment in the house sustainable.

In order to do this, however, we have had to register ourselves as a “provider” and obtain an ABN; we have basically had to set ourselves up as a company, with a full set of policies and procedures; and more recently we have had to go through a full audit. We struggled with all of this, and continue to struggle with the burdens of SDA, particularly as we have much involvement in our daughter’s life, and not only have the challenges of having the responsibilities of this company, but also had to deal with the fallout of having to part ways with several care providers – who have had difficulties themselves in providing appropriate care for our daughter.

But we should not have had to do this. We are just parents, at retirement age, with no experience in business. We had no wish to be setting up a business: we just wanted a secure place for our daughter to live.

SDA might be appropriate for corporate investors, and even for some families. But it is not appropriate for many families. There needs to be another way for families to receive help in having suitable accommodation built for participants who are family members.

Further, the “SDA price arrangements” are rigid, and do not allow for young people who simply cannot live with other participants. There seems to be no allowance for a young person to live in a house by themselves with carers. Yet this is desperately needed. If an investor is prepared to fund this sort of vital accommodation, then SDA should be available. There are cases where psychiatrists as well as care providers would absolutely say that a young person cannot have other participants with them. Neither is it appropriate for family members to live with that young person forever. Families already contribute a huge amount of time and energy to their loved ones, with little appreciation of the hard work, lack of sleep and little time off – even when they aren’t directly caring, they always have the worry of their loved ones. That never goes away.

The above doesn’t even start to address the issue of the participant’s choice and control over their own lives, which people who don’t have a disability take for granted, and was a principal objective of the NDIS.

In addition, recent price rises in SDA do not reflect large increases in building costs, and we would strongly suggest that SDA funding needs to be urgently reviewed to encourage investors and families to be able to assist those who are in desperate need of accommodation, and indeed make it a viable financial consideration.

**SIL, Independent Living Options etc**

We have found that in the rural area of northern Tasmania where we live, there is a “thin market” for SIL, Independent Living Options etc. There seems to be only a handful of providers. The lack of competition leads to a situation in which, from our own experience and that of other families, some (most?) providers are attracted to the “honey pot” of very substantial NDIS funding, but offer only sub-standard services, and are not responsive to the needs of participants – in particular, participants with severe intellectual disabilities. It also seems to us that there are problems in recruiting and training enough support workers who are capable of providing “high intensity” support.

It is sometimes suggested to us that we could “self-manage”. However, we have no family members or anyone else who could step in to take charge of our daughter’s plan when we are no longer able to do so. So we, and many others, are dependent on providers that are well established and can be expected to continue operating into the future.

Given the poor standard of support from many SIL providers, at least in thin markets such as northern Tasmania, we have three suggestions.

First, auditing of SIL providers needs to be hands-on: looking at the services they provide “first hand”, rather than at printed policies and procedures that may or may not translate into how services are actually delivered.

Second, consideration should be given to allocating separate funding to selected providers in rural and remote areas, so that they do provide services of appropriate quality to participants, including those with severe intellectual disabilities. In other areas of the economy, where there is market failure, the government steps in to rectify this. We believe that the market has failed here, and special action is required.

Third, more needs to be done to ensure that there is a pool of workers capable of providing high intensity support, throughout the country, including appropriate salary packages to place a more appropriate value on the essential work these support professionals provide.

Sue and Stephen Ferris

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