



Secretary: Carolyn Vimpani
REAL Incorporated
8 Woodhouse Rd
Doncaster East Vic 3109
Phone: 03 9842 4489
0418 504 264
Email: vimpani@bigpond.net.au

Incorporation AOO 317 18C

DGR Status

ABN 11 846 675 799

Report to the Joint Standing Committee on the National Disability Scheme

Public Hearing November 8 1.00-3.30
Melbourne

REAL Inc

REAL is a small charity which for 22 years has offered opportunities for social contact and support for adults with intellectual disabilities primarily in the Manningham area. (Postcodes 3105-3114). The group meets every Tuesday evening and members are also supported at other times when required. We have a volunteer Committee of Management, no paid administrative staff and three support workers primarily financed through Manningham Community Grants

Scope of this report

- 1. Process to become scheme participants*
- 2. Service provider Transition to the NDIS*

1. PROCESS TO BECOME SCHEME PARTICIPANTS

Background:

The Committee of REAL approached VALID and conducted a series of information sessions over the last 12 months. These were useful and enabled families to begin planning for their NDIS interviews.

The issues that came up for these families included:

- How do I know if I am registered?
- Who should come to my meeting?
- What documentation do I need to take to the meeting?
- How do I get this documentation from services? (Some services will not disclose fee structures)
- How do I manage my money?

REAL believes that the letter to families should be far more supportive and make simple suggestions as to how to approach the NDIS planning sessions. Most families were overwhelmed by the amount of information available, the conflicting advice from providers, and by the terms used.



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Some examples of distress:

- A letter to say that NDIS process would not be proceeding as the agency had been unable to make contact. The agency had used the wrong phone number in contacting the family who were at work during the day. An alternative number had been provided. This caused unnecessary anxiety. An advocate from REAL followed this up.

Issues at the meetings:

- The LAC having a very limited knowledge of the implications of living with an Intellectual Disability, and one LAC confusing an Intellectual Disability with a Psychiatric disorder.
- A parent being told that NDIS would only be available for one disability where the potential participant had both a documented Intellectual Disability and Physical Disability which both necessitated core supports.
- The LAC not thoroughly reading the material provided by the family and in one case not wanting to access the material prepared, with great care, by a family.
- A LAC interviewer who did not arrive for the scheduled meeting causing huge anxiety for an already anxious parent.
- Being told in the interview that the participant's current ISP package would not be matched due to 'so many demands on the NDIS'. Note: The participant's goals under the NDIS were modest, in keeping with the NDIS, and in line with the existing ISP package.
- The area of transport is causing considerable confusion and distress. Not all adults with intellectual disabilities can safely use public transport. Parents tend to provide this where they are able. However, as parents age they cannot manage and increasingly rely on taxis and paid services. The transport allowance is totally inadequate in many cases, especially for participants living on the metropolitan fringe or in rural areas or totally reliant on paid transports.

NOTE: Not all interviews were negative and there were some very supportive LAC's who encouraged the families.

Areas of Greatest Concern:

1. Children with disabilities in main stream schools are not getting told that they need to register. (Information from Principals is not being directed to families). Families are frequently finding out from other parents.
2. Families from non-English speaking background do not always easily understand the forms and processes. As soon as it is known a family's second language is English they should be offered individual pre-planning support meetings.



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3. Families where both parents and children are potential NDIS recipients are overwhelmed and do not know where to start. This applies especially to parents who may have difficulties themselves with literacy and with the concepts involved in the NDIS. Such families need a 1:1 support person to assist with planning and implementation
4. Individuals who have a cognitive disability, no family support and are in supported accommodation. Considerable confusion about responsibility for preparation and signing of the NDIS plans.
5. Older carers, age 70+ who are told they will have to access the Portal electronically and if they can't, are told to get a relative to access it. Not all older people have a network of family support. Further such information as is on the portal is private and the carer may not want others to access it. It is essential a non-electronic format is available. Being told to go to a NDIS centre is no help as this can be difficult, especially for frail carers.
6. The lack of access to a draft of the NDIS package before it is finalised. Being able to access a draft would enable carers /participants to identify areas where there is potential difficulty.
7. The wait of up to 4 months to know the outcome of the NDIS Planning meetings is too long.

2. SERVICE PROVIDER TRANSITION TO THE NDIS

The organisation REAL Inc, (Rights Employment Accommodation Leisure) was not in receipt of regular funding under HACC or from DSS. Rather it has relied for the past 22 years on obtaining Local Government Community grants and a nominal fee to participants. In moving to a structure to become a NDIS Provider it has proved to be a mammoth task for our volunteer committee. Issuing invoices, taking bookings, structuring fees, providing transport are a task undertaken without any administrative budget, administrative support or office space

Our organisation already had in place most of the infrastructure required in terms of policies and processes and the NDA has been supportive in directing what needs to be undertaken for registration. However, this may not be achievable meaning a fantastic local service will no longer be sustainable.



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People choosing NDIA management due to age, lack of computer skills or just because they are tired and it is easier, will not be able to claim the costs involved in accessing our service unless we become a provider.

In planning for the introduction of NDIS I believe the needs of small important grass roots organisations has been overlooked. REAL has an important part to play in enabling adults with intellectual disabilities to identify and be supported in following their interests but we will need administrative support to remain viable.

CAROLYN VIMPANI
On Behalf of the REAL Committee of Management