

Making Lives Real: Too Many Questions, Not Enough Action!

Meeting the individual supported-living needs of people with disability is not easy. The core questions are who is best placed to make decisions about how people with disability will be supported and, subsequently, who will have to bear the consequences of the decisions made?

Firstly, some thoughts on words and definitions. People with disability and their families frequently talk about their lives being seen as a whole. Ministers and government officials, however, divide people's lives into segments so that they can be easily administered — this does not reflect the real circumstances of how people live and, as a consequence, people's lives become artificial to suit bureaucratic rules.

Accommodation support and respite are two such artificially constructed segments. People with disability and their families prefer the term 'supported living'. For example, if someone receives in-home accommodation support or in-home respite what is the difference? From a bureaucratic point of view, the first is for the person with disability and the second is for their family but, from the whole family's point of view, this is an artificial division bordering on the ideological. It also means they have to go to different places/processes and, in some cases, to governments to get support, when the reality is that the support the person receives is exactly the same no matter what the name! This is but one example of how the lives of people with disability are not real lives but constructed lives (lives that bear no real resemblance to the lives lived by ministers and government officials).

So the question becomes: How can people with disability and their families have real lives and who should decide what is a real life?

The Commonwealth Government is currently consulting on the supported accommodation component of its Disability Assistance Package. Again, the Commonwealth Government has divided supported accommodation and respite into two totally separate components. On what basis and for whose benefit?

The discussion paper associated with the consultations has been described as a 'mess' and as 'chaotic'. The paper is confused, and anyone trying to fill it in will become *very* confused. Most of the 37 questions require detailed responses, yet the paper does not provide a framework to assist people to look at the questions and frame their answers within reasonable constraints.

Our primary questions are:

1. What is the legitimate role of governments? and
2. What do we know about the funding, purchasing and provision of support that delivers good lives – ie, outcomes which are flexible and provide quality supports?

The answer to the second question is already sitting on Minister Brough's desk. Disability Ministers commissioned the Social Policy Research Centre of the University of New South Wales to produce a report on: "Effectiveness of Supported Living in Relation to Shared Accommodation". Why is the information in this report not included in the discussion paper? Why has the report not been made available to assist people to make informed responses? Surely some, if not many of the questions that the discussion paper asks, will be answered by this evidence-based research!

This is not the only piece of research that the Government already has before it, which also includes *Interaction* Vol.19#3: “Presenting the Evidence”. Why haven’t the officials of the Department of Families, Community Services and Indigenous Affairs (FaCSIA) collated all the available research and presented it to inform the discussion paper?

How people spend their money is a matter for them. The Government though must spend taxpayers money in a manner that delivers good outcomes – they should not be driven by ideology but by evidence-based research.

It is important to reflect for a moment on the meaning of ideology:

i-de-ol-o-gy (n)

1. *a closely organised system of beliefs, values and ideas forming the basis of a social, economic or political philosophy/program.*
2. *a set of beliefs, values and opinions that shapes the way an individual or a group such as a social class thinks, acts and understands the world.*

The discussion paper is an ideological document and, as such, is deeply flawed. To ask people for their opinions, views or ideas without providing references to research and evidence that will inform the discussions that people will have is dishonest as it deceives people into thinking that all options will lead to a good life and/or that people will eventually get what they want. This is not the case.

The evidence is clear that, to meet the accommodation support needs of people with disability and where appropriate their families, people with disability must have control over what support they receive and how they receive it. Is there any other way? Are bureaucrats and politicians any better than people with disability and their families at deciding what support people should receive and how they receive it? In answering this question, we must remember who will bear the consequences of the decision! The concept of subsidiarity is important – ie, decisions should be made by those closest to the decision’s implementation.

To enable people to make decisions about their lives, there are a number of elements that must be in place:

1. Adequate funding – the Commonwealth’s commitment to meet the needs of all people with disability aged over 40 living with parents over 65 is welcome as it addresses the under-funding issue for this group and enables the other elements to be implemented.
2. Individualised funding based on assessment and banding of funding to meet support needs - the Commonwealth Government already implements this in its employment support program.
3. Option of self-managed funding - this is the third element to ensure that people with disability have control over their lives.

This brings us to the first of our primary questions: What is the legitimate role of governments in the funding, purchasing and provision of support services?

It is the role of the Commonwealth Government to ensure that people who need support receive it in an effective way. In spending taxpayer funds, it is reasonable for the Government to have:

1. eligibility criteria;
2. an assessment process that addresses the support needs of individuals;
3. an allocation of funds on an individual basis; and
4. simple accountability measures for ensuring that people get the support they need and that the funds allocated are spent by/on the individual concerned.

Beyond these, there are legitimate questions about the role of governments and hence what are the legitimate relationships. For example, should support providers have a contract with the government or with the person receiving a support? What are the costs (both financial and to people with disability) involved in the different contract relationships? What are the benefits in people with disability (and where appropriate their families) having control of their funds and hence entering into and negotiating the contracts they need for support. These are important questions and it is essential that FaCSIA and the Minister place any proposals before the Commonwealth Auditor General and the Office of Best Practice Regulation to have the costs and benefits of any proposals tested.

People with disability and their families urgently await the release of the “Effectiveness of Supported Living in Relation to Shared Accommodation” report and the deliberations of the Commonwealth Auditor General and the Office of Best Practice Regulation.

This issue of *Interaction* reviews positive lives for people with disability. In a major paper, the outcomes of deinstitutionalisation are reviewed and the positive changes that have occurred in the lives of many people with disability. The second paper looks at a range of models that provide good outcomes for people with disability. These show what is possible if people with disability and their families are given control to make their lives real!

FEEDBACK !

The Australian Institute on Intellectual Disability
would welcome feedback
(either as a Letter to the Editor or an article)
from readers, particularly people with disability and their families,
with their views/comments and experiences
regarding the important issue of
Accommodation for people with disability.

We look forward to hearing from.

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