

Sunshine Movement Inc.

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DISABILITY CARE and SUPPORT INQUIRY

SUNSHINE MOVEMENT INC.

SUBMISSION

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Submission to the Productivity Commission

Review on Disability Care and Support Inquiry

Sunshine came into existence over 3 years ago as a result of a discussion paper issued on Succession Planning by the Commonwealth Government Department of Family And Community Services and Indigenous Affairs (FACSIA). A group of concerned individuals and aging parents of sons and daughters with primarily intellectual disabilities worked together to respond to the discussion paper.

Following further assessment and consultation it was becoming increasingly apparent that there was a huge unmet need for term of life accommodation and support services for adults with disabilities. As a result this group formed an association which was named Sunshine Movement to develop a strategy to address this unmet need. On 9 March 2007 Sunshine was incorporated in the State of Queensland.

Sunshine Movement Inc is a not-for-profit organisation with the prime role of undertaking benevolent activities for people with disabilities, seeks to encourage, support and provide appropriate accommodation, and services to them ensuring that they are able to live in a loving, secure and nurturing environment which will enrich their lives.

Without doubt the single greatest concern of our members as aging parent/carers is securing a good future for their disabled son or daughter.

Parents and carers have attempted to make comprehensive plans but have been drowning in a morass of legalese, form-filling, bureaucratic musical chairs, wall-to-wall agencies designed to help with everything their child needs *except* the thing that they most need as aging parent/carers of sons/daughters with severe disabilities – life term supported accommodation options that will provide a situation where their disabled son or daughter feels valued, and can live in an environment that is viable and sustainable. A strength of this concept is that it is community based, reinforced by their circles of support, with the aim of improving the individual's level of independence and thus their quality of life, where they can help by using and exercising the abilities they do have and learn new skills.

It is very important that families are empowered to direct the succession planning process with professional assistance as may be required. It is never too early to start this planning process.

It is well known that under the existing government policies the unmet need will never be met. In simple terms the severely disabled can not live without government support, and under the current system there will never be enough public funding to meet that need. So to deal effectively with this whole problem will

require a huge change in government policy particularly at State level. The current situation where crisis intervention is the "norm" is not at all appropriate. It is too expensive and we must move to a situation where:

- There are effective partnerships established with all stakeholders including the families, service providers, developers, financial institutions, and government.
- Governments stop micro managing the whole system and delegate much greater powers to act to the competent service providers,
- Governments primary role should be to set policies, impose standards, allocate public funding, monitor performance and contract the operational aspects through competent service providers as appropriate.
- Governments do not consume disproportionate amounts of the disability budgets on their own activities that do not add value for the people with disabilities.
- The system is proactive and not just reactive.

This would greatly reduce the level of staff and facilities required in the public service and in turn free up significant funding that could be applied to meeting the need. It would also improve the efficiency of the service agencies that currently need to devote significant time and energy in dealing with unnecessary bureaucracy. The present situation where the government deals on a case by case basis at a very detailed and personal level is grossly inefficient. The aim should be to measure the success of the program outputs and impact and not on the micromanaging of the inputs.

There needs to be more flexibility in how Government funding for disability services are allocated. Most service organisations are organised on the basis of the funding they receive (which is tagged), and this limits their ability to drive new innovations and develop more effective ways of delivery the much needed support services. The more progressive service organisations see the issues but do not want to bite the hand that feeds them because of the possible threat of losing funding.

The truth of the matter lays in the fact those parent/carers and the organisations that provide direct services are the best placed to know what is needed and are also more able to respond to changing circumstances.

It is very clear that ideally, the focus on accommodation and support for people with disabilities is a vision of empowerment, independence and inclusion into the community. It has come to our attention that housing environments such as group homes or cluster accommodation dwellings in the one area is not easily accepted if these are mainly occupied by people with disabilities. Areas largely occupied by people with disabilities are not considered to be encouraging community inclusion. However families and family members of sunshine believe that part of the planning process should also be driven by a 'person centred approach', having an understanding of the individual's needs and not just what the government or disability sector considers is appropriate or not. Aging parents and their sons and daughters with disabilities know what is needed for them to be able to achieve their goal of living a fulfilled life, and this may include being surrounded by networks of friends and family members in dwellings of similar proximity.

Sunshine family members with disabilities are today already valued members of the community and have achieved amazing goals throughout their life, and will continue to overcome barriers for years to come. We believe that to be able to address the unmet need of quality supported independent living for sons and daughters of ageing parents, will also require having a more 'person centred approach' and a better understanding of each individual's needs.

An example is the importance of a planned transition to independent supported living for adult sons and daughters with severe disabilities. Yet there are currently no funded programs that specifically address the transitional aspects. Succession planning is very important in developing the most appropriate options and a key part of this should be the staged transition to supported independent living. This period of transition allows for the testing of the mix and matching process for cotenants, the evaluation of how much support is really needed, and the assessment of specific skills training that can be undertaken. This transition process is aimed at ensuring the best possible arrangements for viability and long term stability.

To be able to address the unmet need in respect to providing adequate services and life term supported independent living for sons and daughters of aging parents, will not only require innovative changes to current government policies, but also better ways in which the available resources can be applied.

A National Disability Scheme, properly set up and funded, is a concept we support as this should be significantly more effective in addressing the unmet need.