

**People with Intellectual Disability, McCall Gardens Community Ltd.
and facilitated by NSW Council for Intellectual Disability**

**Submission
Community Affairs References Committee Inquiry**

Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

May 2010



**McCall Gardens Community Ltd.
10-32 Terry Rd.,
Box Hill NSW 2765**

Committee Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House Canberra ACT 2600

Dear Sir/Madam,

McCall Gardens Community Ltd. operates a large residential facility in semi-rural, north-west Sydney. It is an accommodation support service for men with intellectual disability, many of whom have been institutionalized for a great portion of their lives and who are now ageing.

The residential service was originally developed in the mid 1950's by families to address a complete lack of formal support available for people with intellectual disability to live in the community as adults, independent of the family home.

McCall Gardens asserts that this style of accommodation support no longer delivers the outcomes nor achieves the aspirations of people with a disability for an *ordinary life*. By its nature the institution significantly reduces opportunity and quality of life outcomes for people, despite best intentions, planning, hard work, loving family members and well-trained support staff. McCall Gardens has been actively seeking to develop community living options for people, and currently supports one home in the community. Five people with intellectual disabilities have successfully achieved full community membership and have built for themselves greatly enhanced lifestyles and positive outlooks for their futures.

This submission will address, in both video and document forms, what is important to people with disability from McCall Gardens *now*, as they enter middle age or their senior years. This informs further discussion on their experiences as decision-makers, achievers and contributors, as well as planners for the future. They ultimately challenge governments and society to listen and respond to their very ordinary, reasonable desires for the future.

People with a disability, the storytellers in this submission, have interests, desires, needs and aspirations which we all recognise as common to every member of our community. However in many cases they have been limited to a great degree in pursuing and achieving them by societal and systemic factors, rather than lack of personal capacity.

The men have been disadvantaged on many fronts throughout their lives, including; limited or no education opportunities, reduced health care supports, reduced opportunities to challenge and extend themselves and limited exposure to lifelong contact with a range of people in a variety of settings, which generally supports many of us to continue our own development long after we conclude our formal education and begin to move through significant life stages .

They have also been disadvantaged by the paucity of opportunity to explore and build their capacity for charting their own life course; having major goals, experiencing successes, making mistakes, solving problems, with whatever support would be suitable for them individually. Their life journey has largely been steered by systemic lack of support and resources rather than any kind of self-determination. Despite this the people with disabilities encountered in this submission remain stoic and determined that things must and will improve for them.

As they age, these people are facing a critical bind. As people with intellectual disability continue to fitfully emerge from segregated settings , to take up their rightful places in society, they are also facing a real threat of inappropriate re-institutionalisation as they age.

People still living in institutional settings are also at risk of being forced by lack of flexible funding and support options to transfer across from one style of institution directly into another when their health needs increase. This is a matter of urgency for ageing people with intellectual disability currently experiencing declining health or ageing issues.

To be able to plan ahead, people with intellectual disability who are ageing require :

- **Real accommodation and support options to make decisions about.** 50 years on from the establishment of McCall Gardens, and 30 years on from the Richmond Enquiry, there are still no real options for people who would choose to live away from the family home, or whose families can no longer care for them. These options should be consistent with the general community's expectations of a decent life. Once these real options are available then as for the general population, support to age in place should be afforded. Living in residential aged care (a nursing home) is considered a last resort.
- **Individualised support, tailored to the person.** That is not too much, not too little to live full and decent lives in the accommodation style of their choice, for as long as possible. This includes support for current and changing health needs.

- **Sensitive, flexible, responsive support from a variety of trusted sources to make plans and decisions.** While not made explicit in the body of the submission because of sensitivities to existing supports available, it is conceivable that people with intellectual disability may need independent support and advice. A variety of viewpoints can open up real possibilities.
- **To be offered, and continue to be offered opportunities to enhance capacity for active participation and contribution.** Many people with disabilities who are ageing are more capable than at any other time in their lives. A harmonious meeting of concepts of increasing and maintaining independence and community engagement, as well as active ageing should be applied across disability and health/aged care service systems.

Please find the following elements of this submission for your information and reference:

- **“There’s a lot to tell you” – PDF document**
- **“There’s a lot to tell you” – Video in 5 Chapter Files:**
 1. “Storytellers from McCall – some things that matter”
 2. “Storytellers from Ivy Ave – some things that matter”
 3. “Decision-makers”- having real options and the right support
 4. “Achievers and contributors – getting better and better” and “Planners”
 5. “Challengers – what we think you could do next”

The contributors to this submission warmly recommend the Inquiry Committee to viewing their stories and would welcome the opportunity of meeting with Inquiry Members to explore in more detail their personal perspectives on this important matter.

Yours sincerely,

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Chris Eagleston
Chris Harwood
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and

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