

Disability Care and Support inquiry,  
Productivity Commission,  
GPO Box 1428, Canberra City ACT 2601

### **Background**

Being the parents of a child with an intellectual disability has had its ups and downs. The additional time, energy, resources and patience required to do the best for your child is difficult and taxing. But, not being able to project or confidently plan for a rich, fulfilling and independent life for your child becomes overwhelming.

Because of the nature of the education, funding and support structures for people with disabilities, every new milestone, in their development, is shrouded in another maze that has to be negotiated – another fight to obtain or access the resources needed to support the next stage of development.

Our son was born with Down syndrome 20 years ago. He attended Early Intervention from 12 months old and after much searching was accepted in a mainstream Primary School which he attended to year 6. We had to fight even harder to have him accepted at a Special School (secondary) because his I.Q. test score was too low. Finding work experience and a work placement couldn't be managed by the school so it was left up to me to do.

But despite all of this David is a success story. Currently he is working two day per week at Waverley Industries (assembly and packaging), is working two days per week as a trainee at our local Safeway store and attends a literacy/numeracy course one day per week. David has been learning to play the guitar for the past three years and we have just been successful in getting him involved in a music group which we hope will end up in a band or music ensemble.

David is socially competent, travels independently on routes he's familiar with, has good cooking skills and is developing independent living skills. However the future is not necessarily bright and rosy nor easy to visualize with any certainty.

To get assistance under the present system we have to wait until our family is in a critical state, no longer able to look after David and then the best we can hope for is that what's available is suitable for him.

What we would like to do is plan when David moves into a suitable independent/semi-independent living situation while we are still able to support him both physically and emotionally, especially during the transition period.

### **Funding/Eligibility**

Eligibility for support should be established as early as practical - when the disability is acquired or definitely diagnosed.

### **Management**

A long term 'Individual Action Plan' should be mapped out (by those concerned) as soon as possible, identifying - goals, progress path, how the goals are to be achieved, who is responsible and how the funding could be best used to achieve the goals. This doesn't have to be an inflexible document but should give an idea of what needs are to be met how and by whom and who will need to bear the responsibility for ensuring this happens. How success is to be measured could be negotiated at this stage as well. Small changes that are

made to the plan and are within the funding could require notification only whereas larger changes may require a 'plan review' before they can be enacted.

In the case of 'at birth' disabilities, many of the needs may already be met by other organizations and support may not be required till much later. If existing funding is pooled into the one scheme things like aids, intervention, etc would be identified and supported immediately.

The 'Individual Action Plan' would be part of the assessment of what funds would be required and at what times they could be accessed.

As with any system there is a danger that structures will be developed and that clients will be forced to fit for economic and management reasons. However the economic savings and ease of monitoring does not compensate for the fact that often it is only a rough fit and the specific needs of the disabled person are only partially met. Attaching the funding to individuals and empowering them to manage these as well as their personal resources, as a whole could give better outcomes and a greater sense of control about their lives.