

SUBMISSION TO THE PRODUCTIVITY COMMISSION

- DISABILITY CARE AND SUPPORT
- From Marge & Jeff Bishop

BACKGROUND

We are the parents of a daughter with Down Syndrome. We are aged around 80 and our daughter is nearly 40. She has always lived with us; works 13 hours week spread over 4 days; is able to feed, dress, toilet, shower herself; and enjoys a good family life. She is over weight, has poor eyesight, is getting slower with age, has little concept of money and becomes easily disoriented. We never leave her by herself over night.

INTRODUCTION

- . We are members of "Stepping Stones For Life", which is forwarding a separate submission, which we support.
- . Stepping Stones For Life, in turn, contributed to the UnitingCare NSW.ACT submission, which we also support.
- . This submission is supplementary to those two.

AIM

Our aim is to give a brief overview of the effectiveness of disability services, as we have experienced them, and to offer some constructive suggestions. Our comments are made in chronological order.

BIRTH

The traumatic experience for parents of learning that their newly arrived child has a serious disability is profound.

- SUGGESTIONS.

- . There should be a system in place under which parents of children diagnosed with a disability, whether at birth or later, are not only counselled and informed, but supported emotionally and, where appropriate, financially.
- . A subsidised, community agency may well be more suited to this task than a government one.

PRE SCHOOL & CHILD CARE

The pre school experience is as important for children with a disability as it is for other children.

- SUGGESTIONS.

- . Provision be made in Child Care legislation for the needs of children with disability.
- . Funding for extra facilities, extra staff and specialised staff training should be provided.

SCHOOL YEARS

Our daughter had excellent schooling in special schools. Facilities were not always perfect but the staff were highly professional and dedicated. Importantly, programs were in place to maximise contact with students from mainstream schools. The trend towards integrating children with disabilities into mainstream school can be helpful for some of the more able children, but not all.

- SUGGESTIONS.

- . Integration of children with disabilities into main stream schools is fine in principle but is not always the best option; . it has benefits for some students, and provision should be made for those students; . It is necessary in areas where there are insufficient numbers to warrant a special school.
- . Well resourced Special Schools, with specially trained teachers, do an excellent job: Don't abandon them.

EMPLOYMENT

The regularity, routine, professionalism and networks all disappeared when our daughter left school. She sat at home for long periods. She had a succession of jobs, some interesting and fulfilling (e.g.

helping in a child care centre), some degrading (cleaning wash rooms and toilets on building sites). Recently she had a wonderful job in an ironing enterprise. Eight supported and four unsupported employees worked in the business with a shop front and much contact with the public. Four months ago the agency closed it because it wasn't paying for itself. She was placed in a new position where there are many more supported employees and less support workers; much more of a sheltered workshop model. Retrograde steps like this should not be happening.

Fulfilling employment, giving satisfaction and purpose to life, is desirable for all people, not least people with a disability.

Employers report that people with disabilities are usually more reliable, regular, punctual, dependable and loyal workers than the average. Normality and integration into the wider community is more easily achieved in the work place, than in their accommodation arrangements.

- SUGGESTIONS.

- . Much greater effort must be made to place people with a disability in normal work places alongside regular employees.
- . The benefits of employing people with disabilities should be more widely advertised.
- . Funding should be made available for more support workers.
- . Subsidies or other incentives for employers should be expanded.
- . A change in culture is needed to encourage more employers to see it as a moral responsibility to provide such employment.

ACCOMMODATION

The accommodation question is the most difficult. There is no simple, or single, answer.

We had large institutions for many years, organised on the factory model with emphasis on efficiency and procedures rather than on individuality and human values. These were replaced by smaller units, e.g. group homes. In theory, these were a good idea but if the management style didn't change they were still institutions with rules, regulations and revolving staff rosters. Some were successful, some weren't. More recently, independent living has been promoted as the panacea. This too, is a good idea in theory and it works for some people, but it too, has limitations. e.g. isolation and loneliness, and usually higher costs. There is no perfect model.

- SUGGESTIONS.

We think that the following fundamental principles should be acknowledged and adopted by governments.

- . Every human being is unique, including people with disabilities;
- . There is an infinite variety of types and degrees of disability;
- . All human beings, including those with disabilities, are entitled to live in a manner of their choosing, provided it does not adversely affect other people;
- . There is no "one model fits all" solution to the accommodation needs of people with disabilities;
- . All models have their merits and demerits;
- . No model will be effective unless it is managed correctly;
- . Each individual with a disability, together with his or her family, is entitled to choose the model perceived by them to be the best for that individual.

Some obvious accommodation options include; . living independently and alone; . living independently in a unit or bedsitter in a complex with provision for some communal living; . sharing a house or unit with a non-disabled person; . sharing a house or unit with another disabled person and a carer; . sharing a home with compatible friends under a family governance model;

FINAL COMMENTS

1. The needs of people with disabilities are immense. The cost of meeting those needs, nation wide, is enormous. The major cost, so far, has been borne by parents. The obligation on ALL Australian residents to meet those needs is vital, not only for the benefit of the individuals and

their families, but for the ethical and moral standing of the nation. Governments must commit to this.

2. Governments, in responding to the financial challenges, have two choices, either (a) increase taxes (highly unlikely in current political climate) or (b) redirect existing tax income from other less needy areas. (and there are many.) 3. Provision of funds, by itself, is pointless unless allocated correctly. Higher quality care requires higher qualifications and higher pay for staff. We must be prepared to meet this.

4. More emphasis needs to be given to education, as distinct from training, in the disability sector in Australia. How many universities conduct relevant courses? How much serious research is carried out?

How rigorously are various ideologies examined before being adopted?

We can do much better.

5. We think there is a great deal of potential for developing more constructive partnerships between government and non-government bodies. Stepping Stones For Life is a good example of what can be done when a community body (St Margaret's Uniting Church providing facilities, management, volunteer helpers and personal support) and a government body (Disability ACT providing guidance and financial support) work constructively together.

6. The introduction of the proposed National Disability Insurance Scheme (NDIS) is essential for the protection of the most valuable people in our society. No one knows when their family may be adversely affected by disability, by accident or by birth. It is a logical extension of our health care scheme. We implore the Commonwealth Government to commit to and implement the NDIS as a matter of urgency.