



## Australian Society for the Study of Intellectual Disability COMMUNIQUÉ

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### Introduction

This communiqué results from a recent ASSID workshop, “20:20 Vision”, where two nationally recognised leaders in the field of intellectual disability, Professor John Taplin and Mr Peter Millier, examined the progress that has been made in the past twenty years and identified issues that will influence directions for the next twenty years.

Many worrying signs exist which forecast a bleak future for people with intellectual disability.

It is time for political leaders, families, services, advocates and communities to confront these issues if people with intellectual disability are to truly participate in and contribute to the South Australian community. Overwhelmingly, the workshop came to the conclusion that political and moral leadership was vital if much of the progress of the past twenty years was to be built upon rather than lost.

### The Past

The late 1970s and early 1980s produced two reports in South Australia that set the ground for significant reform in the field of intellectual disability. *“The Law and Persons with Handicaps”* (the Bright Report) and the *“Intellectually Retarded Persons Project”* (the McCoy Report) were groundbreaking documents, not only in South Australia, but within Australia generally, and set the scene for dramatic changes to the lives of people with intellectual disability. Until that time, services were institutional, disjointed and there was no locus for planning and development.

The reports led to the formation of the Intellectually Disabled Services Council (now the Intellectual Disability Services Council) guided by a set of principles that have lost none of their relevance in the ensuing twenty years.

The South Australian experience was strengthened by the passage of the Commonwealth *Disability Services Act* 1986 which espoused a number of positive developments “to assist people with disabilities to integrate into the community”, “to achieve positive outcomes” and “to promote in the community a positive image of persons with disabilities and enhance their self-esteem”.

The foundation of the two reports and the Commonwealth Act, supported by political leadership and will, saw a revolution in the provision of services to people with intellectual disability, much of which was focused on the role of IDSC, which was given the task of reshaping services for people with intellectual disability. As a moral

underpinning, the principle of normalisation gave significant impetus to services that included provision within the community, access to generic services, involvement of people with intellectual disability in decision-making about their lives, and the move away from segregated service provision.

This movement continued until the mid 1990s when this direction was sidetracked by the prevailing economic rationalism paradigm implemented through the funder / purchaser / provider model (Options Coordination).

## **The Present**

Whilst recognising the past gains in the field of intellectual disability, the forum realised that, in many areas, the impetus of the 1980s had slowed or stopped. In particular, it noted that:

- the lives of many people with disabilities are still characterised by isolation, loneliness and rejection;
- there is a lack of developmental opportunities in the lives of many people with intellectual disabilities,
- the prevailing Options Coordination system tends to promote the purchase of personal care and respite over the provision of developmental and behavioural services;
- people with intellectual disability are now more likely to be seen as problems to solve than as citizens to support;
- there are still many examples of exploitation, neglect and abuse;
- most people with disabilities still have their lives managed by others;
- most people with disabilities networks tend to consist of service providers and professional relationships rather than friendships;
- education provisions and prospects for people with disabilities are still not very good;
- some people with intellectual disabilities have real jobs but most do not;
- there is a disproportionately higher percentage of people with disabilities in the mental health and criminal justice systems;
- the needs of many people with intellectual or physical disability are currently not being met by the service systems – much of the burden still falls on ageing parents/carers;
- the health needs of people with disabilities are greater than in the population generally;
- people with disabilities are now living much longer and will need to access generic aged care services;
- institutions are being reinvented as aged care and forensic units;
- the new understanding of the human genome may be used to justify sterilisation and euthanasia;

- problems will be created through any merging of administrative responsibility for services to people with all kinds of disability, or merging disability services with aged care services in a broader model of community care (if this was to occur);
- the implications of larger societal changes (e.g. pressures on families, human service professionals, government budgets and universities with their role in generating a research agenda and evidence based practice) are affecting and will continue to affect people with intellectual disability;
- inclusive/integrated approaches to service delivery, whilst very desirable, reduce the quality of data on people with intellectual disability;
- a reduction in specialist knowledge resulting from reduced numbers of professional staff.

Many of these issues are already affecting the lives of people with intellectual disability overseas and interstate, and their effects are similarly impacting on service delivery in South Australia. Interestingly, although both Commonwealth and State legislation and various policy documents espouse choice, the grim reality is that there is no choice and that the move of a person with intellectual disability from the family home rarely occurs before family breakdown.

Many of the current “solutions” within the sector seem to have their genesis in cost cutting. Testimony to this are:

- the move to larger services – the SNAP assessment is based on a five-person group home model;
- the move to dealing with the problems associated with intellectual disability (keeping bad behaviour off the streets), rather than assisting people with intellectual disability towards citizenship;
- the bringing together administratively of people with disparate disabilities when their needs are quite different and when overseas evidence clearly identifies the negative effect this is having on people with intellectual disability;
- the placement of many “difficult” clients in Strathmont Centre, often in makeshift accommodation.
- the misuse of “normalisation” arguments to justify cost cutting (e.g. cutting services specifically for people with intellectual disability based on arguments for the use of generic community-based services without consideration of whether such services can adequately meet the needs of this group).

## **The Future**

In examining how the field could move ahead, there was agreement that the following should be addressed:

- the importance of demonstrating positive outcomes i.e. through evidence-based service delivery;
- the need for recognition that positive outcomes should focus on service user outcomes in addition to economic-based outcomes;
- the need for methodologies to show that services are cost effective;
- the need for new and more genuinely flexible, client focussed approaches to service provision;

- the need for service providers to work with parents and advocates (e.g. to overcome parental fears about deinstitutionalisation);
- the continuing need for effective partnerships between people with intellectual disability, parents, professionals and academics;
- the need for training and employment of more professionals so that current standards of specialised knowledge are enhanced;
- the continuing need for community education and good access to information about the place of people with intellectual disability in the South Australian community;
- the continuing need for research;
- a reaffirmation of values that see the person with intellectual disability as a citizen who needs support rather than a societal problem to be solved;
- real resourcing in early intervention services – not only focused on the preschool years but enabling the early intervention work done in the preschool years to be carried on so that the gains made by children with disabilities are not then lost. We already know that early intervention services can have both clinical and economic outcomes, reducing reliance on long term and often life long care.

## **In Conclusion**

Drawing upon the experience of the past while engaging in a clear analysis of the present situation enables us to project into the future. The directions we take and the outcomes we choose depend on the decisions we make today.

To regain the momentum of the 1980s, there needs to be a rekindling of political will and leadership.