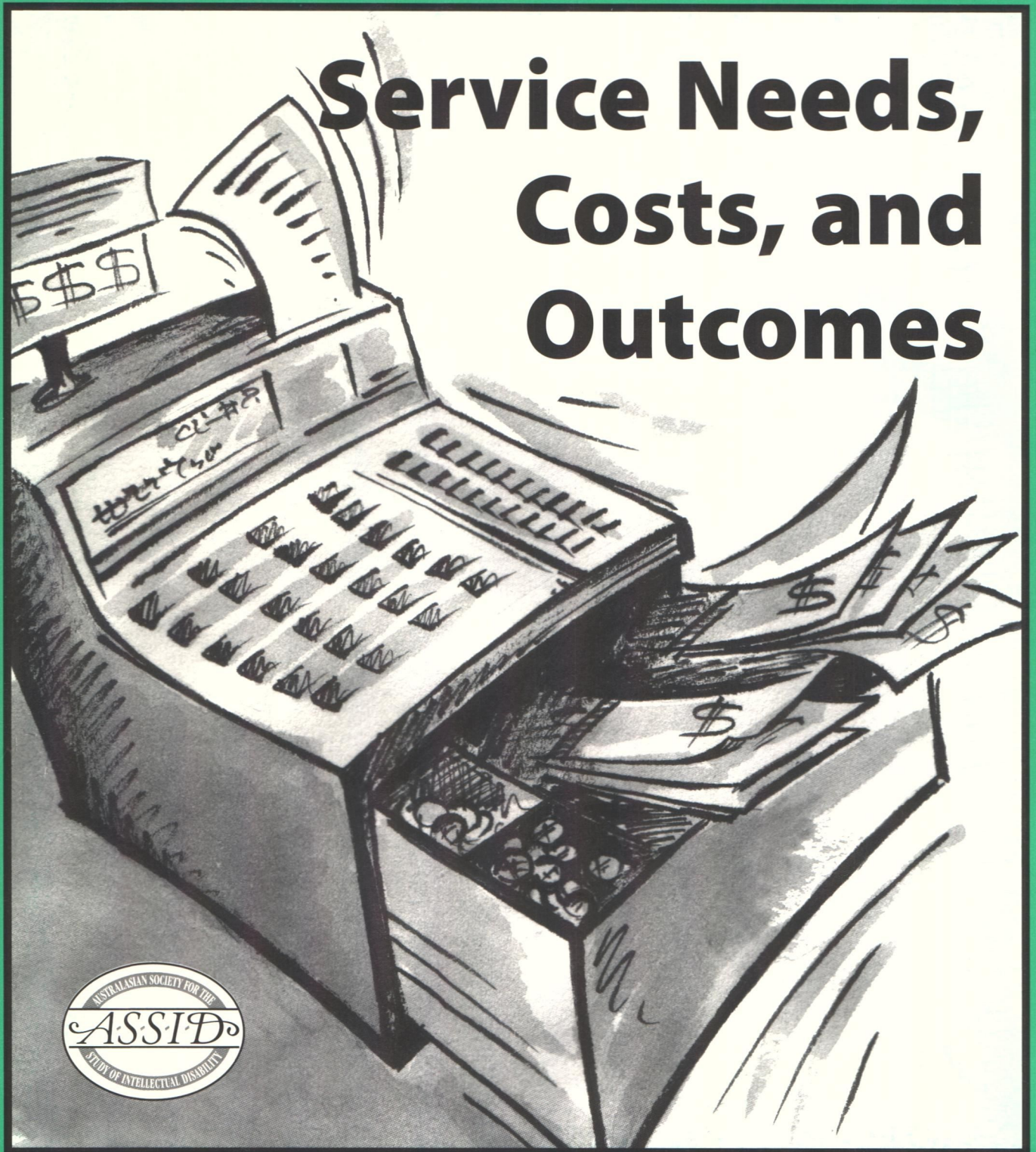


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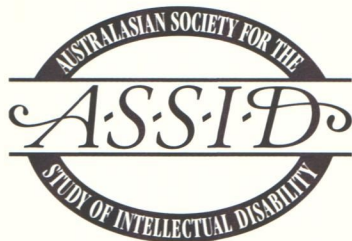
IDA

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Intellectual Disability Australasia

Service Needs, Costs, and Outcomes



Magazine of the Australasian Society for the Study of Intellectual Disability



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Correction:
 The March 2005 issue of IDA was incorrectly labelled. It should have read Volume 26, Issue 1, March 2005

Editorial



Some of you may remember when Don Grimes was Minister for Community Services in 1983 and released the report of the Handicapped Persons Programs Review (HPPR) that eventually led to the introduction of the Disability Services Act (DSA) in 1986. It was an exciting and challenging time that raised awareness about disability and led to a significant injection of additional funds to provide support services. As Don Grimes has said:

“We hoped to produce changes which would create an environment, both a social and economic environment, which would encourage consumer involvement, which would produce effective and accountable changes, but above all, be flexible, allow for changes with time. We tried to get away from that situation where mutual dependency of those with disabilities and those who cared for them. This was a terrible limiting factor inhibiting change. So, we set out on the Handicapped Persons Programs Review.” (Plenary Address, Disability with Attitude International Conference, 16 February 2001).

The HPPR and the DSA brought significant changes to funding arrangements. Services became more accountable through a set of Disability Services Standards that were introduced in 1993. A fundamental issue for many services at this time was the level of funding they received in order to provide appropriate levels of support and assistance to their service users and to meet the Disability Services Standards. We have seen various funding formulae introduced to distribute limited resources in a way that, it is hoped, will deliver the best possible services to people with disabilities and their families.

Articles in this edition by David Felce, Neil Kirby and colleagues, and Roger Stancliffe and Charlie Lakin provide our readers with a wonderful opportunity to consider funding and service quality issues from different perspectives. David Felce examines whether staffing and staff support in community based accommodation services is meeting the needs of service users. Neil Kirby, Julia Harries and Roma Guscia consider issues related to the assessment of support needs, an issue that has vexed many over the years. Roger Stancliffe and Charlie Lakin analyse needs-based funding experiences in the USA and reveal the complexities involved in achieving ‘equitable’ funding arrangements. If you are interested in extending your reading about needs-based funding, Roger and Charlie have edited a book that has recently been released called *Costs and Outcomes of Community Services for People with Intellectual Disabilities* available through Elsevier Australia for \$63.80.

Deb Keen

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Support Needs Assessment: Measures and Critical Issues

*Dr Neil Kirby (pictured), Julia Harries, Roma Guscia
Disability Research Unit (DRU), Department of Psychology, University
of Adelaide*

Reforms to disability service provision in Australia and overseas, particularly since the International Year of Disabled Persons (IYDP) in 1981, have been driven by a range of factors. These have included normalization and deinstitutionalisation, and a growing commitment to enhancing service outcomes, especially quality of life. There have also been concerns with obtaining better evidence on the size and nature of the disability population, including changes associated with ageing, and with the more efficient use of finite resources (Cummins, 1997; DHS, 2000; Luckasson et al., 2002; Parmenter, 1999; Patja et al., 2000; Schalock, 1999). With respect to resources, concerns have continued to be raised about the shortfall in services relative to need, and about whether resources to support people with disabilities are being distributed equitably (AIHW, 2002).

It has been argued that a person centred approach to the assessment and funding of support has the potential to address the needs of people with disabilities more effectively and cost-efficiently (Brown, 1999). Its success, however, depends critically on how well each person's need for support services can be identified (Jenkinson, 1996; Thompson et al., 2002). To ascertain the relative needs of individuals with disabilities and the costs involved in meeting these needs poses significant challenges.

Underlying the move to a person centred approach has been a paradigm shift which has changed the way we perceive people with disabilities (Lord & Hutchinson, 2003). Traditional models of disability have focused on the nature of an individual's disability and associated deficits. Deficits have typically been measured in terms of the absence of adaptive behaviours and the presence of maladaptive behaviours. Numerous adaptive behaviour scales have been developed to assess these deficits. This model of disability tended to result in the exclusion of people with disabilities from participation in society activities due to their deficits. The paradigm shift in the way disability is perceived moves the conceptualization of disability from the deficit approach to a support approach. Under this disability paradigm individuals are viewed as "people who have a life and need support" to participate in society (Butterworth, 2002 p.85). This concept of

'support' tailored to the needs of the individual underpins the American Association on Mental Retardation (AAMR) and the World Health Organisation (WHO) models of human functioning and disability. These models, which focus on the person - environment interaction and challenge current service practices (particularly tendencies towards exclusion), have led to efforts to define and measure the support needs of individuals.

One instrument developed to measure support needs is the Supports Intensity Scale (SIS; Thompson et al., 2002). Developed by the AAMR, the SIS can be used to establish needed supports, monitor progress, evaluate outcomes and project support costs. The SIS measures support needed in 49 life areas grouped into six subscales (Home Living; Community Living; Life Long Learning; Employment; Health and safety; and Social Activities). Support required for each life activity is measured in terms of the frequency that support is required (e.g. daily), the cumulative amount of time support is required on a daily basis (e.g. 30mins to 4hrs), and the type of support (e.g. prompting) required to participate in daily activities or settings. SIS also has supplemental scales which identify Protection and Advocacy support requirements and additional support requirements associated with the presence of exceptional medical and behavioural needs. While SIS, like adaptive behaviour scales, deals with typical performance in everyday activities, the AAMR report that SIS and adaptive behaviour scales measure related yet different constructs, thereby requiring different measures. However, in contrast to adaptive behaviour, the nature of the support need construct is not well understood thereby making the systematic assessment of support needs difficult.

A number of different support need assessment instruments are used within the disability sector across Australia. One such instrument is the Service Need Assessment Profile (SNAP) which was developed in Australia by Gould (1998). SNAP has been designed to provide an objective measure of support and it seeks to inform decisions about how to distribute funding across residential services for people with different disabilities in a manner which ensures equity, transparency and rationality. SNAP identifies individual needs in 29 areas of daily living

continued page 4

Support Needs Assessment: Measures and Critical Issues *continued*

measured across five support domains; Personal Care Needs, Physical and Health Supports, Behavioural Support, Night Support and Social Support. Ratings of support required are entered into a computer software program, which produces a support profile, detailing the time allocations for staff support to assist in each area of need, an identification of the type of night support required (e.g. active, sleepover, or none) and behavioural support requirements (e.g. behaviour program). The support profile information can then be used to establish roster requirements and a profile of support costs per individual.

Over recent years, the Disability Research Unit (DRU) at the University of Adelaide have been involved in collaborative research project with the South Australian Department of Families and Communities (DFC) to address the issue of the measurement of support needs. In particular, this research has involved an analysis of the reliability and validity of SNAP, in addition to addressing the broader aim of determining the theoretical structure of support needs and methods of measuring this construct. This research has involved an examination of a number of instruments, including the Inventory of Client and Agency Planning (ICAP; Bruininks *et al.*, 1986), an adaptive behaviour scale widely used in the US for funding services for people with intellectual and developmental disabilities, and the recently developed SIS. This research has revealed a number of critical issues associated with the measurement of adaptive behaviour and support needs. In particular, the following issues have been highlighted:

- Problems with low or unreported reliabilities in various support assessment instruments with higher reliabilities generally reported for adaptive behaviour scales.
- Available assessments have frequently been developed on the basis of a single disability type (e.g., intellectual disability, acquired brain injury) and consequently lack the flexibility or breadth of coverage to assess the diversity of needs that may accompany multiple disabilities.
- Assessments are not in the context of the person's stage of adult life or the physical environment (group home vs. institutional setting).
- Assessments provide a static "snapshot", rather than a dynamic account of the individual's current functioning. They do not assess fluctuating needs or anticipate changes that can be expected to occur, for example, as a result of skill development, aging, or a health condition that is progressive.
- Assessments tend to be either insufficiently detailed for individual program planning or too detailed and

time consuming to complete to be useful for resource allocation.

- The underlying support model is frequently a dependent maintenance model lacking a developmental/training orientation. Consequently there is generally little consideration given to the type and level of staff expertise required and potential sources of support.
- The nature of the support need construct is less clear than that of adaptive behaviour which complicates the process of undertaking systematic assessment of support needs.
- Low feasibility in some assessment instruments (for example, some are not easy to use to or are considered to be too time consuming)
- Some assessments give insufficient recognition to the preferences of the individual being supported, in terms of service options despite the assumption that these instruments will contribute to their improved quality of life.

In June 2004 the Disabilities Research Unit was successful in obtaining funding from the DFC and the Australian Research Council to develop an assessment system that aims to address the critical deficiencies that limit the usefulness of existing instruments for the assessment of support needs. This approach will be evaluated against a number of widely accepted criteria that have emerged from previous research. In particular, requirements for a comprehensive support needs assessment system include the following:

1. Assessment of both support needs and adaptive behaviour (since adaptive behaviour assessments are generally more reliable and objective).
2. Assessments of different disability types, levels of severity and ages to ensure the assessment system is applicable for individuals with a wide range of levels, types and combinations of disabilities.
3. An assessment system that allows for different levels of assessment detail (e.g. for the purposes of determining eligibility for services, for allocating funding resources, and for program planning)
4. An assessment system that is sensitive to changes in adaptive behaviour and support needs over time and in different environmental contexts.
5. An assessment with wide user acceptance.
6. An assessment system that produces efficient and effective quality of life outcomes for funds provided.

To the extent that the methodology meets these criteria, it will be employed in the first instance by the South

Australian DFC as the basis for allocating resources to support persons with different types and combinations of disabilities.

To date the work of the DRU has largely focused on discussions with members of the disability sector to determine their requirements for an assessment system. Much of the feedback received has been critically important for understanding the needs of the sector and those in receipt of services. Recognising the importance of the disability sectors' contribution to the development of an assessment system, we invite interested parties to contact us at the Unit for information about the project and on how they can be involved. It is our belief that working together is essential for achieving an assessment system that is equitable, and that addresses the diversity of ongoing needs of people with disabilities in a more effective, efficient and equitable way.

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ASSID Distinguished Service Citation

Nominations for the ASSID Distinguished Service Citation are now open for 2005.

Nominations must be received at The Secretariat by Monday 11th July 2005;
E-mail assid.national@bigpond.com

Nominations should be in writing and, ideally, submitted electronically.

There is no specific application form that needs to be completed. However, enquires can be made to The Secretariat: assid.national@bigpond.com; PO Box 84 Rosanna, Victoria, 3084, Australia; Tel (Aus) 1800 644 741 or from outside Australia Tel. 61 + 3 + 9499 9244.

The nomination should be accompanied by a brief biography of the person being nominated. This biography should include details that establish the nominee's distinguished contribution to A.S.S.I.D., which had enhanced A.S.S.I.D.'s profile and / or operation. The nomination should be signed by at least two current ASSID members.

Nominations will be reviewed by the Australasian Board and successful nominees announced during the Australasian Conference at Auckland, in October.

NOTE - Current members of the Australasian Board are not eligible for nomination.

Needs-based funding: Experience from the USA¹

Roger J. Stancliffe & K. Charlie Lakin

Research and Training Center on Community Living
University of Minnesota

Why Focus on Needs-Based Funding?

Allocating available funding *equitably* among service users is a basic value that should underpin all funding arrangements. Funding distribution should be fair, consistent, and based on valid methods for determining funding levels. Except perhaps in instances of specific short-term expenditures that meet a specific individual need or goal, persons with fewer self-care and living skills, more challenging behaviour, or more serious health problems are thought to need, *and are assumed to receive*, more staff support and so require greater per-person expenditure to provide appropriate services.

However, studies have reported widely varying relations between expenditure on services and the characteristics of service users. For example, Stancliffe and Lakin (1998) found that, for 116 former institution residents in Minnesota, individual expenditures on community service provision were *not* significantly related to service-user characteristics, but were strongly related to funding stream, and to structural features of service provision (public or private auspice, residence size, residence age, staff ratio).

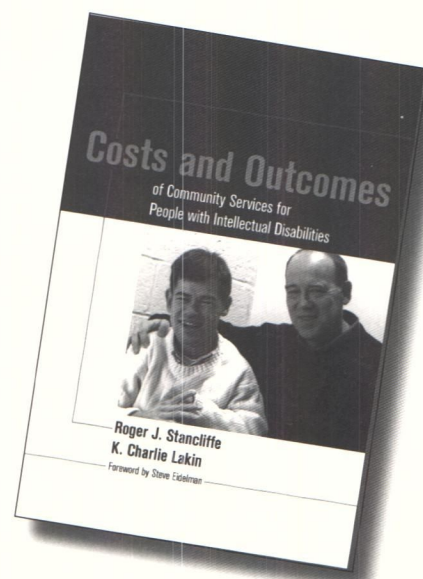
Traditional funding arrangements of congregate facilities have been based on rate schedules and facility operating costs, cost caps, local negotiation with service providers, and historical reimbursement rates, often with little specific attention to the current needs and characteristics of service users beyond basic eligibility requirements. Such funding arrangements have not been needs based and have resulted in inequity and inefficiency.

Inequity. Service users with similar needs may receive greatly differing funding and services. Likewise, service providers serving individuals with similar needs receive differing funding and so can afford differing staffing levels. Under such funding arrangements, service providers experience substantial disincentives to serve individuals with high support needs because they are too costly to serve effectively given the available funding.

Inefficiency. If there is no rational way of allocating funding, it is difficult to know, on a policy level, if services are costing too much or too little. Likewise, it is more difficult to plan and cost new services that meet service-users' needs

¹ A previous version of this paper was presented as: Stancliffe, R. J., & Lakin, K. C. (2004, November). *Needs-based funding: Experience from the USA*. Paper presented at the 39th annual conference of the Australasian Society for the Study of Intellectual Disability (ASSID), Adelaide.

effectively and fairly, and/or to respond to suggestions that service costs are excessive.



US Trends in Individualised Funding

Efforts to establish greater equity and efficiency in service financing in the US have confronted state officials with the need to develop methodologies for equitable allocation of funding to individuals. Moseley, Gettings, and Cooper (2005) reported that, in 2002, some form of individualised funding was in place in nearly 74% of the 43 US states they surveyed. In this paper we compare the way two US states, Minnesota and Wyoming, have approached the task of making their funding systems more needs based.

Minnesota

The Medicaid Home and Community Based Services (HCBS) program is the main source of funding for intellectual disability services in Minnesota. In Minnesota, the state allocates funds to counties according to the number of service users (and their support needs for post-1995 enrollees). The county negotiates with service providers regarding service costs for individuals and can spend more or less than the state provides for the individual, with the expectation that the total expenditures for services for all individuals will not exceed the total amount the state authorises the county to spend.

Before 1996 the state provided the same amount to counties for each service user *regardless of support needs*. The *Waiver Allocation Structure* (WAS) was introduced in 1996 to make funding more needs-based. The WAS provides one of *four* substantially different levels of funding to counties for each *new* HCBS recipient, with Level 1 = \$US222.87, and Level 4 = \$US126.74 per day in 2002. Irrespective of support needs, counties continue to receive the same amount for all pre-1996 service users (the lowest WAS funding level). For persons entering the HCBS program post-1996, funding levels for each individual are based on an assessment of physical, functional, medical, and behavioural characteristics and support needs. The assessment uses an instrument developed by the Minnesota Department of Human Services that has long been used to assess all new service recipients, and to

regularly reassess all existing service users.

Lakin, Hewitt, Larson, and Stancliffe (2005) analysed actual state expenditure on services for each individual HCBS service user in Minnesota, and revealed that the WAS funding level accounted for only 3.1% of variation in expenditures on services for all individuals. WAS funding level accounted for 8.1% of variation among the 31.3% of sample members who had been assigned funding under the WAS (the other 68.7% of sample members being enrolled in HCBS before this funding system was implemented in 1996). This difference (i.e., 3.1% versus 8.1%) indicates that funding initiatives are more effective in making the funding system more needs based if they are applied to *all* service recipients, rather than being restricted only to new entrants to the system.

The same personal characteristics that were used to place people into one of the four WAS categories, when reemployed as *continuous* scales (rather than a few discrete levels), accounted for 15.3% of variability in individual HCBS expenditures. Adaptive behaviour and challenging behaviour were the strongest predictors, and were much more predictive of expenditure than the four WAS categories derived from them.

Expenditures were strongly tied to service utilization (31.6% of variance), with users of expensive, fully-staffed group homes having much more costly services than residents of other settings. This association (31.6%) is much higher than the association with WAS funding level (3.1%) or personal characteristics (15.3%), indicating that, in Minnesota, expenditure was related to service users' individual needs to a limited extent.

Wyoming

Changes in funding of community developmental disability services in Wyoming were described in detail by Fortune et al. (2005). Fortune et al. reported that, in 1995, Wyoming adopted a 5-level system linked to individual "service scores" from the *Inventory for Client and Agency Planning* (ICAP) (Bruininks, Hill, Weatherman, & Woodcock, 1986). Service scores provide an index of support needs based on a weighted combination of assessments of *adaptive behaviour and challenging behaviour* (higher scores = greater independence and less need for support). As Table 1 shows, this funding system was similar to Minnesota's *Waiver Allocation Structure*.

Many stakeholders in Wyoming found the 5-level approach to be problematic because it was seen as too crude and arbitrary. Small differences in ICAP scores could result in major differences in the funding available to support individuals (e.g., a service-score change from 19 to 20 resulted in a 50% reduction in funding). Fortune et al. (2005) analysed actual state expenditure on services for each individual under the 1995 model (Table 1) and found that half the variation in expenditures was associated with *unknown* factors. Only a little over a third (37%) associated with differences in support needs of individual service users.

Table 1:

Wyoming's 1995 HCBS funding system for community residential services (adapted from Table 11.1, Fortune et al., 2005).

ICAP Service Score Range	Daily Rate	Staff Ratio
1-19	\$US165.00	1:1
20-39	\$US82.00	1:2
40-59	\$US55.00	1:3
60-79	\$US41.00	1:4
80-100	\$US33.00	1:5 or more

It quickly became evident that a new, more individualized approach was needed to replace the 1995 model illustrated in Table 1. Fortune et al. (2005) describe the statistical model, known as DOORS, which was developed in response to this need, and is now used throughout Wyoming to allocate funding to individuals. The DOORS model is based on each service user's individual characteristics (*15 variables*) and the person's living, working, and service use arrangements (*7 variables*) (but *not* the costs or characteristics of specific service providers). The derivation and application of this model is described in detail by Fortune et al.

Each DOORS variable has a statistically derived weighting that is used to convert the person's score on each variable into an overall *Individual Budget Amount* that is *unique* for each service user. This means that small changes in scores on a variable result in small changes in funding, because funding is continuously variable, not simply one of a few widely differing funding levels as in Minnesota.

Analysis of actual expenditure on services for individuals under the DOORS model (Fortune et al., 2005) showed that almost half (47%) the variation between individuals was associated with assessed differences in the individual characteristics of service users. There was also a substantial association with the services/supports used (28%). Both individual characteristics and service-use variables are employed by DOORS when allocating individual funding in Wyoming. Overall, the DOORS model accounted for 75% of variability in individual expenditure on services in Wyoming, with only a quarter (25%) associated with unknown factors. This is an exceptionally strong relation between support/service needs and individual expenditure and shows that, in Wyoming, funding is substantially needs based.

The Wyoming experience reveals that funding arrangements that are based on individual assessment of support and service needs offer a basis for rational and equitable allocation for public money.

Conclusions

Comparison of funding arrangements in Minnesota and Wyoming suggests that systems of individual funding will be more needs-based (i.e., equitable and efficient) if:

- a) needs-based funding systems are applied to *all* recipients, not just those entering the system for the first time;

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NZ

by Marleen Verhoeven

A strategic planning day with the council was held in Auckland to discuss the vision and future focus of NZASID. A good brainstorm was had, including clarification of job descriptions of the different executive functions and the way forward for the organization. Identified difficulty is the geographic, spread-out nature of NZ. Regional groups will not likely be successful – focus groups are more likely to succeed when built on existing, thematic groups e.g. dual disability or psychology. Suggestions for improved communication with the council and membership were discussed. We also spoke about succession planning with Angus planning to leave the NZ executive and Olive being approached for the Australasian presidency, thus leaving a gap in the NZ executive. The inclusion and acknowledgement of self-advocates was also on the agenda.

The preparation for the ASSID conference in October is in full swing with the confirmation of keynote speakers and the call for abstracts. A social programme is also starting to take shape. For more information: www.assid-conf05.org.nz

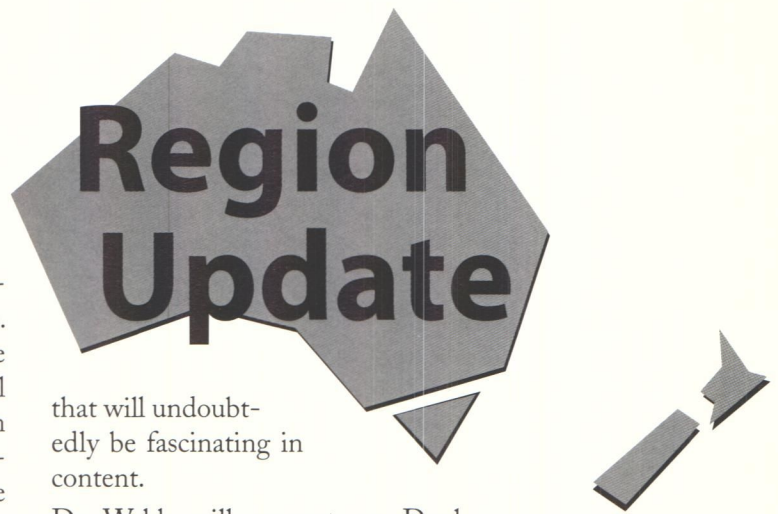
Victoria

by Daniel Pennefather

ASSID Victoria would like to thank all those who gave feedback by returning the member survey that was distributed recently. The information has already assisted with strategic planning at the Australasian level. At a regional level we are also currently engaged in strategic planning, with a specific focus on the needs and expectations of members.

In December 2004 the Victorian region of ASSID reported concerns to the government about proposed changes to state disability legislation. More specifically, the report highlighted some of the implications for service provision and community inclusion as they applied to people with intellectual disabilities. We are delighted to report that the Victorian Minister for Children/Minister for Community Services, the Hon Sherryl Garbutt announced the intention to release an exposure draft of the proposed legislation in response to repeated requests from like-minded organizations in the disability sector, including ASSID Victoria.

ASSID Victoria, in conjunction with the Disability Studies Division at RMIT University have begun working on the fifth Direct support Worker conference for 25 and 26 November this year. The theme for this year's conference is **Five years on: Strengthening support**. Speakers will include Tom Shakespeare from the UK and Dr Olive Webb from the Institute of Applied Human Services in New Zealand. With a long list of publications on topics such as ethics, disability and current genetic research, the social model of disability as well as the sexual politics of disability, Tom will present a keynote address



that will undoubtedly be fascinating in content.

Dr Webb will present on Dual Disability. Dr Webb has established a reputation as a leader in quality management developments, specialising in the design of systems that benefit both the health sector and the community at large. Visit www.iahs.org.nz for further information about Dr Webb's work. For further information about the conference contact Sue.Mason@rmit.edu.au.

NSW & ACT

by Tony Tinlin

The NSW and ACT regional group have been working on the Regional conference which is to be held at the University of Canberra on the 28-29 July. The theme of this year's conference is Working Together. The conference is aimed at enhancing communication between those people who are providing direct support either residentially or as a member of a specialist support service including health, educational, vocational, leisure and advocacy services to people with intellectual disabilities.

The Conference has as the keynote speakers three people who have and continue to make a significant contribution to the field as practitioners, teachers and researchers. They are Dr Lihah Pengra an anthropologist working in the USA, she is well known to many workers in the field. Among her most recent publications is "Your Values, My Values: Multicultural Services in Developmental Disabilities".

Dr David McConnell who is Acting Director of the Australian Family and Disability Studies Research Collaboration, David also lectures in the Faculty of Health Sciences at the University of Sydney. David is known internationally for his research, conducted in both Australia and the United Kingdom, in the field of parenting and intellectual disability. David has a particular interest in "working together" and holds Australian research Council Linkage grants with the NSW Departments of Ageing, Disability and Home Care and Community Services, with the aim of promoting collaborative practice and the provision of more timely and appropriate supports to families where a parent and/or a child has a disability.

Dr Keith McVilly is part of the team working at the

Centre for Developmental Disability Studies at the University of Sydney. Keith is the author of the recently published "Positive Behaviour Support for People with Intellectual Disability: evidence-based practice, promoting quality of life". Keith is also involved in the development of a professional approach to the provision of residential support to people with intellectual disability as well as his research around friendships for people with intellectual disabilities.

There will also be a range of other presenters who will no doubt provide interesting and stimulating papers. The conference is usually a good opportunity for the NSW & ACT members and those working in the field to get together and share information and enjoy good company. Anyone interested in being involved (and/or presenting papers for the 2005 conference) should contact a member of the committee.

The NSW & ACT committee have also commenced work on the 2006 Australasian Conference which will also be held in Canberra.

This year's AGM will be held at the Canberra conference, at a time to be announced.

For further information contact Tony Tinlin 0260231800/ Mobile 0428865465/Fax 0260 416940 OR John Brown at Joh1213@bigpond.net.au.

SA

by Richard O'Loughlin

On 26th April, ASSID (SA) held its first event for 2005: the launch of a self advocacy training resource package. This 'package' arose from activity at the Australasian conference in November 2004, where, as an integral part of the conference proceedings, there was a self-advocacy stream. As part of this stream a workshop was held that invited the people of the 'Our Voice' committee to reflect upon their experiences as self advocates and to provide information to others about the types of issues they may need to consider if they are self advocates, have a role in supporting self advocates or are planning on starting a new self advocacy group. The 'Our Voice' SA committee is part of a national network organised by the National Council for Intellectual Disability (NCID). This workshop was videoed and has subsequently been produced in both VHS and DVD formats. The launch (with wine, cheese, tea and coffee provided) attracted 35 people. This group consisted of approximately 20 self advocates with the remainder coming from the public sector, non-government service providers, advocacy organisations and local politicians. (The Hon Kate Reynolds of the SA Democrats attended). The launch was a success and it is hoped that sales of the package will assist the 'Our Voice' committee in their fund raising.

We are currently negotiating with staff at Flinders University to try and pin down a date for a research showcase event at Flinders.

Tasmania

by Donna Ryan

We have made an enthusiastic start to the ASSID year here in Tassie. A member of our committee has put together a draft power point presentation that will be used primarily to introduce and promote ASSID Tas to organisations and students (in the field of intellectual disability).

Falling out of our strategic plan for 2005/2006 was a unanimous decision to alter Tasmania's ASSID activities by choosing to hold workshops and sponsor training opportunities (by bringing in presenters and speakers of interest from the mainland and internationally) as opposed to the more traditional state conference. Much discussion was held by our committee on this subject (i.e. the benefit of conference versus workshop or other training) and I was pleased to hear at the recent Australasian Board meeting that this view is shared by several other ASSID regions as well.

Excitement is building in regard to the upcoming Australasian Conference in New Zealand in October with several of our members actively promoting the conference and planning to attend.

Queensland

by Chris Montgomery

A dinner was held at the Chifley on George on Tuesday April 12 with guest speaker Christine Bigby speaking to the topic "Is Successful Aging the Same as Living a Successful Life?" Chris was excellent and people greatly valued having access to her. It was enjoyable to get together and have a good discussion about these issues. One person remarked that they 'really ought to join ASSID because you get such good content not just political or ideological stuff.'

A special general meeting was held on the same night to endorse the new constitutional template for A.S.S.I.D. This was endorsed unanimously. Follow up notification of Office of Fair Trading will be completed shortly.

The *Sharing the Road* conferences will be held in Brisbane and Townsville. June 27-29 in Brisbane at the Nathan campus of Griffith University and July 13-14 at the Townsville campus of James Cook University. The theme for the conference this year is *Supporting Diversity*. Highlights include workshops by Dr. Lilah Pengra of the United States and Autism Spectrum Disorder specialist Dr Wendy Lawson. Keynotes in Brisbane include anthropologist and sister to Maryla (who has an intellectual disability), Dr. Jani Klotz (NSW), Diversity Consultant Margherita Coppolino (Victoria), Indigenous service user, Byron Albury and University Chaplain Bob Harriman (who delivered a very moving paper at the Montpellier conference). In Townsville, they include local personality Ross Williams, councillor Dale Parker and Ethnic Community Care Links Manager Sandra Seto.



Support in the Community: Staffing and staff support in relation to service user needs

David Felce

Welsh Centre for Learning Disabilities

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The last 30 years has seen a radical change in support and accommodation arrangements for adults with intellectual disabilities living independently of their families, from predominantly large, remote institutions to community-based housing. Such reform was prompted by the recognition of the unacceptably poor standards of care and quality of life experienced by service users in existing institutional services. Some of the most central concerns related to staff availability and what staff did or didn't do, including:

- a perceived lack of staff working directly with service users, particularly with those with the greatest needs for support,
- low rates of attention given by staff to service users,
- lack of developmental stimulation when staff did attend to service users, and,
- a neglect of providing the opportunity for meaningful activities in which service users could engage (e.g., Burg et al., 1979; Duker et al., 1989, Felce et al., 1980, 1986; Moores & Grant, 1976; Rawlings, 1985).

To take just one illustration, the problems of the extent and quality of attention were graphically demonstrated by an early study in the UK by Wright and her colleagues (1974). On average, each of 16 children in 5 institutional living units only received attention for 13 minutes during a 4 hour observation period (5.6% of time) and no attention for 227 minutes (94.4% of time). What little attention they received was overwhelmingly neutral in tone and content (94.5%). Only 0.4% of the attention received was rated as positive (equivalent to only 3 seconds in 240 minutes), while the remaining 5.1% was regarded as negative. Studies since that time have reported a similar picture.

Many of the apparent explanations for such failings - underfunding and difficulties in staff recruitment leading to poor staff-to-service user ratios, medical or custodial models of care, poor staff attitudes, low expectations of service users and the limitations of the institutional environment - were explicit targets for reform in the deinstitutionalisation movement. Reform in the UK has been associated with

increased resource investment and improved staff-to-service user ratios, adoption of a social care, 'ordinary life' model allied to a new vision informed by normalisation ideology and the principle of inclusion, and an emphasis on community integration and normative buildings, locations and furnishings. Moreover, there has been a trend towards smaller, more staff intensive settings over time (Felce & Perry, 2004).

Against this backdrop of change and given the problems highlighted at the outset, this paper addresses the extent to which the move to supported community living has brought improved support for service users in practice. It specifically examines four issues:

- How do staffing levels relate to service user needs?
- Has the level and nature of attention that staff give to service users changed?
- How well matched is that attention to service user needs?
- Has higher resource or staff input resulted in improved support for service users?

How do staffing levels relate to service user needs?

Felce et al. (2003) and Stancliffe (2005) have specifically examined the relationship between staff input per service user and service user characteristics. The former found only 26% of variation in staffing related to service user characteristics, mostly strongly to level of challenging behaviour, while the latter found no significant association with adaptive or maladaptive behaviour but significant association with age and psychiatric status. In both studies, factors such as size of residence, service model and provider agency exerted greater influence over costs than the needs of service users. Four studies (see Table 1) have explored why the costs of community based services in the UK vary (relevant to this question as expenditure on staff accounts for about three-quarters of all costs in UK supported accommodation). All show that only a minority of variation in costs per service user is related to service user characteristics and that other aspects of the design of services influence staff input per service user.

Table 1 Factors influencing the cost of supported accommodation

Study	% cost variation explained	Service user characteristics influencing costs	Other factors influencing costs
Knapp et al. (1992)	23%	skills, challenging behaviour	size of residence
Cambridge et al. (1994)	42%	specific skills and challenging behaviour in hospital	
Raynes et al. (1994)	65%	age and skills	length of stay, agency, staff qualifications, quality of setting
Hallam et al. (2002)	51%	age and skills	size of residence, service model, status as tenant, staff qualifications, social climate, activity planning, staff training

Has the level and nature of attention that staff give to service users changed?

In a review of UK and Irish research on deinstitutionalisation, Emerson & Hatton (1996) found that the percentage of time attention was received by service users averaged 4.2% (range, 3%-16%) in institutions, 9.3% (range, 2%-17%) in community units or hostels and 14.8% (range, 5%-31%) in community housing. In general then, there has been improvement. However, even in community housing a service user can only expect to receive attention from staff for less than 10 minutes per hour. Moreover, although levels are double the average in settings towards the upper end of the range, those at the lower end of the range are no higher than average institutional levels or those in the Wright et al. (1974) study quoted at the outset. Some community settings continue to offer very little.

Table 2 summarises average findings from five studies of UK community housing with overall levels of attention near the mean stated above. They show that types of attention which might be equated with the notion of support, encouragement or assistance, are a minority of the attention received and occur for 2-6% of time (1-4 minutes/hour). Although higher than the Wright et al. (1974) study, the level may still be totally inadequate for the effective support of people with more severe disabilities. The majority of attention remains neutral in nature.

How staff spend their time at work has been observed directly. Felce et al. (1998) observed staff working with people with the most severe challenging behaviour in Wales, half of whom lived in institutional settings and half

in supported community housing. They found a broad similarity in how staff distributed their time between categories of activity (see Table 3). Less than 30% of each staff member's time was spent attending to service users or service-user related activity. A subsequent study of a cross section of community housing (Felce et al. 2002a) found a slightly greater proportion of time spent attending to service users on average. However, at the lower end of the range, there were houses in which staff were hardly ever observed attending to service users. Proportions of time spent independently doing housework, administration and 'other' activity were similar to the Felce et al. (1998) results for both institution and house staff. These activities collectively fill about half of total staff time at work on average, considerably more in some settings.

How well matched is attention to service user needs?

One might expect that service users with fewer independent skills would be seen as having the greater need for support, and consequently, receive more attention and assistance from staff. A number of studies have shown this does not occur in practice (Felce et al., 2002a; 2003; Felce & Perry, 1995; 2004; Hatton et al., 1996). People with more severe disabilities do not receive more support; the level of assistance to engage in activities remains at a few minutes per hour. In some studies even, people with greater independence have been found to receive more attention and assistance than people with fewer skills. Overall, staff performance is not well matched to the needs of service users.

Table 2 Extent and quality of attention (% of time per service user)

Study	Nature of Attention		
	Encouraging	Assistance	Other Attention
Rawlings (1985)	6%		7%
Hewson & Walker (1992)		2%	19%
Felce & Perry (1995)		3%	12%
Felce et al. (1999)		4%	12%
Felce et al. (2000)		6%	14%

Table 3 Staff activity (% time per staff)

	Felce et al. 1998		Felce et al. 2002a
	Institution	House	
Attending to service user	16%	21%	31% (3-61%)
Service user-related activity	11%	7%	5% (0-19%)
Housework	15%	23%	19% (1-40%)
Administration	7%	9%	7% (0-29%)
Staff-staff interaction	26%	17%	10% (0-24%)
'Other'	25%	23%	27% (6-70%)

Has higher resource or staff input resulted in improved support for service users?

There is evidence that higher staff-to-service user ratios lead to service users receiving more attention (e.g., Felce et al., 2002a, 2003) but the extent to which each member of staff attends to service users tends to go down as staffing levels increase (e.g., Mansell et al., 19882; Felce et al., 2002a). However, Hatton et al. (1996) found no association between the costs of services for people with intellectual disabilities and sensory impairments and the level of attention from staff which service users received.

The relationship between costs and quality of outcome is at best equivocal. Cambridge et al. (1994) and Hatton et al. (1996) reported no links between costs and outcomes and Emerson et al. (2005) concluded that the associa-

continued page 12

tion between costs and outcome was weak. Service user engagement in activity has been found to be associated with extent of attention or assistance received from staff, but not with staff-to-service user ratios directly (Felce et al., 2002a; 2003; Perry & Felce, in press). There is some evidence that more frequent community activity may be associated with higher staff:resident ratios or costs (Emerson et al., 2005; Felce et al., 2002a), although Stancliffe & Keane (2000) found the opposite. However, there is also some evidence that more choice and greater involvement in household management are related to lower staff:service user ratios (Felce et al., 2000; 2002a, Stancliffe & Keane, 2000).

Clearly, given the experiences of the past, having sufficient staff is important. But the evidence available suggests that there is not a straightforward relationship between more resource intensive services and quality of outcome. Certainly, resource input should not be viewed as a proxy for outcome. Rather, there appears to be a necessity to (a) achieve the correct balance between too few and too many staff, and (b) ensure that the investment in staff resources is translated into effective support for service users who need it. Establishing particular working methods and training staff to implement effective approaches may have an important role to play in this respect.

Training in Active Support

Active Support (Felce et al. 2002b) is one such approach which has been specifically developed to address the inadequate level of assistance given to people with greater support needs and their consequent extreme under-occupation. As we heard from Roger Stancliffe and others at the recent ASSID conference, Active Support is being replicated in Australia. In our own evaluations of the implementation of Active Support (Jones et al., 1999; 2001), we found that implementation of Active Support resulted in service users receiving more assistance, people with greater disabilities receiving more assistance, service users being more constructively engaged in activity (with increases in engagement being related to increases in assistance) and people with lower adaptive behaviour scores deriving most benefit.

Conclusion

The research which I have presented has been mainly drawn from the UK, so readers will need to decide how much the themes illustrated apply to the situation in Australia. In the UK, there is no longer a resource input problem within staffed community housing, although there may still be a requirement to match staff input to the needs of service users more closely and seek to achieve the correct balance between too few and too many staff. Moving to service models with greater flexibility to meet the needs of individuals may have a role to play here (see discussion in Stancliffe, 2005; Stancliffe & Lakin,

2005). The problem of extremely low attention received by service users from staff has also lessened, at least in the majority of community housing services. However, significant concerns about the quality of support people with more severe disabilities receive and about matching levels of support to need still persist. In the UK, deinstitutionalisation was pursued following an 'ordinary life' model which did not stress the need for staff training beyond values and attitudes. It was assumed that staff would not need to learn how to give people with intellectual disabilities effective support once they were freed from the medical model and institutionalisation. The evidence presented here suggests that this assumption was not correct.

In the UK, deinstitutionalisation has required considerable resource investment to be achieved (Felce & Emerson, 2005). Although improved outcome in community services has generally been found to justify the additional costs (Emerson & Hatton, 1996; Felce, 2000), evidence of a direct association between resource input and quality of outcome within community services remains illusive.

Staff training may be the 'missing link'. Active Support illustrates the potential quality of life improvements which may flow from training staff.

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Needs-based funding: Experience from the USA continued from page 7

- b) continuous *individualised* funding amounts are provided (rather than a small number of discrete funding levels);
- c) a specified amount allocated to pay for services is assigned *to the individual*, rather than infusing it into an overall pool to be managed by an intermediate agency for multiple service recipients; and
- d) allocated amounts reflect different circumstances (e.g., people living with family versus in residential settings; children who attend school) that are integrated into the individual rate-setting formula.

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Book Review:

Living, Striving, Achieving

An Australian Perspective on Disability

Richard Brown (Editor)

Newcastle: NSW, Life Activities Inc. 2004

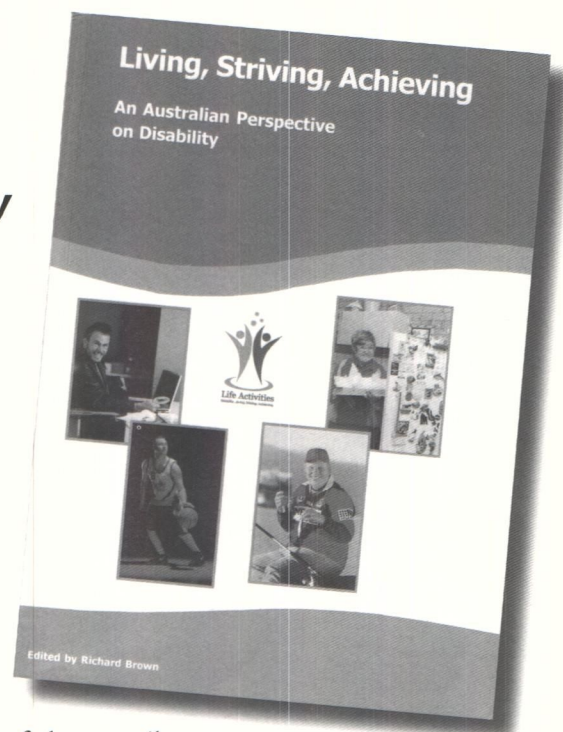
312 pages No RRP

Reviewed by Kim Davies

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This book, published under the auspices of Life Activities Incorporated (a not for profit organization based in the Hunter Valley region of New South Wales, Australia), sets out to be an introduction to the field of disability support for tertiary students and support workers. It is a many-chaptered volume, with contributions organized around two main parts – Concepts in disability and Reflections on disability. It is not a purely academic tome, but rather brings together the ideas and practice wisdom of workers in the field. Topics are many and varied, covering much of the spectrum of work that is disability support. Issues are covered from both a pragmatic and a conceptual/theoretical orientation and it is clear that for the contributors, enhancing the quality of life of people with disabilities and those who care for them, is their overriding concern. Individuals, and the importance of understanding and planning for their unique needs, are an important ongoing theme of many of the book's chapters. This is an important, if mammoth undertaking, and whilst it is true that in its twenty-seven chapters the book covers many of the "myriad aspects of supporting people with disability" (*About this book*), parts of the book are problematic and overall the material is inconsistent in its quality and presentation.

Stronger editorial guidance may have made this a very useful text for its target audience. Editorial support should have at least enabled a better translation of what were previously interactive workshop presentations into book chapters. The book is organized into two parts: Part 1 (Concepts in Disability) incorporates the majority of chapters and covers specific subjects such as behaviour support plans, individual support plans, and the use of the creative arts in individual program development; social justice issues like those relating to health inequity and duty of care; and more general (but no less important) discussions of problem gambling, sexual identity, aging and loss and grief. Part 2 (Reflections on Disability) includes six chapters which present practitioners reflections on their practice as disability support workers. Part 2 is aptly named, as the chapters in this section do reflect its title. To call Part 1 Concepts in Disability is, however, to imply a level of conceptual analysis that is not present



in all of the contributions in this section. Many of the chapters in Part 1 are determinedly pragmatic in their intent, some demonstrate limited critical analysis, others are theoretically 'stale', some are difficult to read because they lack clear introductions and/or conclusions and others are poorly referenced, with references to key ideas not cited in the text and/or not provided in the reference list. Part 1 might be more accurately called Issues in Disability. Each chapter was written to stand alone, which accounts for the diversity of subject matter, one of the book's real strengths. However, the book lacks an introductory chapter or other sort of overview or framework whereby these diverse, individual chapters could be related and interconnected. It lacks a guiding hand. Information about contributors, beyond a list of their formal academic qualifications, would also have helped contextualize their contributions.

Also much of the book is relevant to the work of disability support in New South Wales. Some chapters deal with legislative requirements and/or support services that apply only in that state. This is only problematic because it is not spelt out to readers in the book's introduction. Also, while the book claims to address disability, the majority of chapters are written in relation to working with people with intellectual disabilities. Only two chapters address a different area of disability, namely, Autistic Spectrum Disorders. Again, this is only problematic because the reader is lead to expect something the book does not deliver – the full range of disabilities encountered in disability support work.

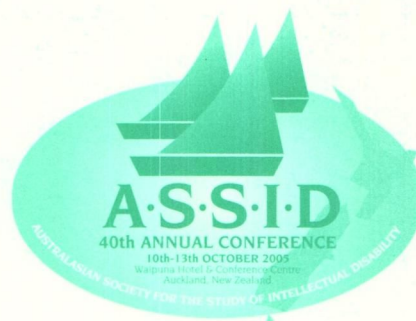
Several of the chapters are outstanding efforts, clear and informative "snapshots ... of life at the interface of theory and practice" (*About this book*). However, on the whole, the book lacks the editorial stewardship that could have transformed it into an informative, expansive text that thereby lived up to the expectations generated by its title.

<p>12 – 15 July 2005</p>	<p>1st Asian-Pacific Regional Congress of IASSID <i>Life course perspectives of research with people with intellectual disabilities: global trends and local strategies.</i> The Howard International House, Taipei, Taiwan Email: service@asiapacificiassid.org Web: www.asiapacificiassid.org</p>
<p>18 – 20 July 2005</p>	<p>2nd National Ageing & Disability Conference: Passion, Power, Practice Hotel Grand Chancellor, Hobart Tasmania (Hosted by ACROD Ltd – Tasmania) Further information: www.acrod.org.au/conferences/a&d2005/home.htm</p>
<p>22 – 23 July 2005</p>	<p>Shared Visions: Exploring the future for disability in Queensland Conrad Jupiters, Broadbeach (Hosted by Warren Pitt MP, Minister for Communities, Disability Services and Seniors). Approximately 300 delegates, from all sectors of the disability community, will come together to actively map the future for people with a disability, their families and carers. Further information: www.iamevents.com.au/sharedvisions/</p>
<p>28 – 29 July 2005</p>	<p>ASSID NSW & ACT Regional Conference Working Together to Enhance Quality Of Life for People with Intellectual Disabilities University of Canberra The theme of the conference is <i>Working together – bringing together the range of direct support staff who assist people with an intellectual disability take their places in society.</i> Enquiries & Abstracts: Tony Tinlin, Regional President or John Brown Tel: 02 6023 1800 Mob: 0428 865465 Tel/Fax: 02 4276 1918 Fac: (02) 6041 6940 Mob: 0428 969737 Post: PO Box 1179, Albury NSW, 2640 Email: joh1213@bigpond.net.au</p>
<p>23 – 25 Sept 2005</p>	<p>Lecture by Professor Robert Stodden on Educational Improvement & Diversity – What is the Place of Special Education? National Conference of the Australian Association of Special Education Brisbane Convention Centre Further information: www.astmanagement.com.au/aase5/Default.htm</p>
<p>28 – 30 Sept 2005</p>	<p>Delivering Better Health Outcomes for People with Developmental Disability Conference Combined International Roundtable of the Health Issues and Mental Health Special Interest Research Groups (SIRG) of the IASSID and Annual Conference of the Australian Association of Developmental Disability Medicine. Carlton Crest Hotel, Melbourne 28-30 September 2005 Keynote speakers include Mike Kerr, Bob Cummins, Sally-Ann Cooper, Tony Holland, Phil Davidson, Dinah Reddihough, Adam Scheinberg, Paulo Selber Further information: www.cddh.monash.org/ and select Developing Better Health Outcomes for People with Developmental Disability at bottom of page.</p>
<p>10 – 13 Oct 2005</p>	<p>ASSID Conference Out of the ordinary? Creativity, Co-operation, Collaboration Waipuna Hotel and Conference Centre, Auckland, New Zealand. Guest speakers: Dr Philip Ferguson, Dr Dan Goodley, Dr Edwin Jones, Dr Diane Ferguson and more Web: www.assid-conf05.org.nz</p>
<p>29 Nov – 1 Dec 2005</p>	<p>University of New England (Hosted by Challenge Armidale Ltd) Inspiration, Innovation, Information: National Best Practice in Disability Conference The conference will feature presentations, workshops, and posters on leading practice in the areas of governance, management practice, ageing and disability, health and well-being, employment services etc. Program, abstract and registration details: www.une.edu.au/campus/confco/bpdc2005</p>

Australasian Society for the Study of Intellectual Disability (ASSID) 40th Annual Conference

10 – 13 October 2005

Waipuna Hotel & Conference Centre
Mt Wellington, Auckland, New Zealand



Theme

***“Out of the Ordinary?
Creativity, co-operation,
collaboration”***

Programme Strands

- ◆ Advocacy
- ◆ Self-Advocacy
- ◆ Health
- ◆ Social, Criminal & Forensic Justice
- ◆ Families & Education
- ◆ Community Living
- ◆ Culture & Indigenous Issues

Keynotes

- **Dr Philip Ferguson**
University of Missouri - St Louis
Out of the ordinary? Creativity, co-operation and collaboration.
- **Dr Dianne Ferguson**
University of Missouri - St Louis
Making research ordinary – debunking its complexities.
- **Dr Dan Goodley**
University of Sheffield, UK
Self-Advocacy: A reliable alliance?
- **Dr Edwin Jones**
Researcher, Bro Morgannwg, NHS Trust; Honorary Fellow, University of Glamorgan, Wales UK
Actively supporting the ordinary.
- **Dr Susan Hayes**
Head of Department, Centre for Behavioural Sciences, The University of Sydney, AUS
People with intellectual disability & their experience of the criminal justice system.
- **Dr Glynis Murphy**
Professor of Clinical Psychology, Institute for Health Research, University of Lancaster, UK
Does treatment help people with intellectual disability who are at risk of offending?
- **Dr Patricia O'Brien**
Director, National Institute for the study of Learning Difficulties, Trinity College, University of Dublin
Bridging the divide between the ordinary and extraordinary.

Symposia

- Led by **Dr Roger Stancliffe**, Centre for Developmental Disability Studies, Ryde, New South Wales, AUS
Community Living Issues.
- Plus more – details still being confirmed

Timelines

- Call for Presentations** now open – visit the website or contact the Organiser
* closes 15 July 2005
- Registration** now open & available online or as hard-copy brochure
* brochures will be mailed out to all ASSID members
* early registration discounts end 1 September 2005

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