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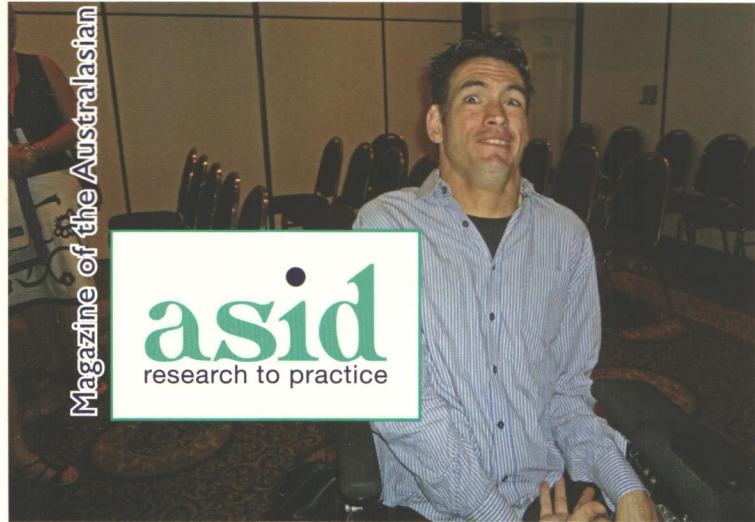
IDA

Intellectual Disability Australasia

2011 conference
person centred planning
Professor Alan Clarke
inter-disciplinary training
retirement planning

Magazine of the Australasian Society for Intellectual Disability

asid
research to practice



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editorial



It seems incredible to think that we are already more than a quarter of the way through 2012. This year promises to be an exciting one for ASID, with major changes underway with the webpage, a new Secretariat and new faces on the Board.

This year's conference will be held in Wellington, New Zealand. This is only the second time that ASID has welcomed delegates to New Zealand for the annual board conference and we are assured of a warm welcome and some interesting debate. The call for papers is well underway and more information can be found on IDA's back page, as well as by googling 'ASID 2012' or going directly to the conference webpage <http://www.asid-2012.org.nz/>

Inside this edition of IDA you will find the Adelaide conference report, several feature articles and information about a newly produced DVD aimed at supporting 'Transition to Retirement' for older people with an intellectual disability.

The debate is growing around the Australian National Disability Insurance Scheme, and inevitably the issues are becoming increasingly political. IDA is interested in hearing from ASID members on this and other important issues for the sector. Why not email your thoughts and comments for publication in a 'members' opinions' section for the next edition?

As always at this time of the year, I invite your feedback on how IDA is tracking and welcome any ideas, suggestions or even an article about some of the innovative work that you are involved in right now.

Best wishes, Sue

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An Evaluation of the Impact of Person Centred Planning

Dennis Robson

Civic Residential Services

Rachel Dickson, Marie Knox, Claire Gore & Minerva Rivas

Centre for Disability Studies

Background

The Centre for Disability Studies (CDS) was approached by Civic Residential Services in April 2009 to conduct an evaluation of their pilot project, which involved the implementation of a person centred approach. It was established that Quality of Life would be the focus of the evaluation, with Person Centred Planning as the intervention to be assessed.

Introduction

Broadly, quality of life is about "having a life that is rich and meaningful to each individual" (Brown & Brown, 2003, p.25). The measurement of quality of life for people with intellectual disabilities has largely come into focus over the last few decades. This has been partially due to the construct's recognition by, and embedment in, state and federal legislation (for example, Disability Services Act (Commonwealth) 1986; Disability Services Act (NSW) 1993. Studies investigating the quality of life of this population are scarce in comparison to other groups, particularly with regard to subjective well-being (Brown & Brown, 2005). Person Centred Planning (PCP) is thought to address "many of the concerns raised regarding the conceptualization and measurement of quality of life" (Butterworth et al., 1997, in Schalock, 1997, p. 7). This method of individual planning is a process that is built on the preferences and dreams of an individual, and ultimately seeks to enhance their quality of life.

PCP is just one component of person centredness; a concept which is described as "both a philosophy and a set of related activities that leads to simultaneous multilevel change" (Mount, 2002, p. xxi). Traditionally, service delivery in the disability sector has been characterised by diagnosis, prescription, assessment of needs and actions to address them (Callicott, 2003). This approach only emphasises what is important for an individual. In comparison with other methods of individual planning for people with intellectual disabilities, PCP is unique in its fundamental consideration of what is important to an individual, balanced with, what is important for an individual.

While there is emerging international evidence that PCP can lead to improvements in lifestyle-based, quality of life outcomes for people with intellectual disabilities

(Robertson et al., 2007), there is a lack of research investigating the efficacy of this planning method (Rasheed et al, 2006).

The following objectives were initially outlined by Civic in relation to the evaluation:

- Establish baseline Quality of Life measurements (qualitative and quantitative)
- Conduct post measurements following the implementation of Person Centred Planning (qualitative and quantitative)
- Comparison of baseline and post-Planning measurements
- Evaluation of the impact of Person Centred Approaches and Planning

Who was involved in the Current Study?

There were four groups of participants involved in the study at baseline, post planning and follow up:

1. Eight individuals who live across two Civic group homes.
2. Family members of the above residents.
3. Support staff for the above residents.
4. Upper management.

The intervention: Person Centred Planning

Each participant was engaged in a PATH (Planning Alternative Tomorrows with Hope) (Pearpoint, O'Brien & Forest, 1993). PATH is a creative and visual process which assists people to plan and work towards turning their dreams and aspirations into real and possible futures. The Pathfinder and the people he/she wants to invite meet together with two facilitators to work through the process.

Measurements

A battery of four tests was selected to collect baseline, post-Planning and follow up measurements.

1. Quality of Life Questionnaire (QOL-Q), Schalock & Keith (1993). The QOL-Q was completed by residents only and contains four subscales: Satisfaction, Competence/Productivity,

continued page 4

- Empowerment/Independence, and Social Belonging. It has 40-items, delivered using an interview format
2. The Choice Questionnaire, Stancliffe & Parmenter (1999). The Choice Questionnaire was completed by residents only and the 26 items relate to how much choice an individual has in their lives. Domains include: Health; Domestic Matters; Staff; Social Activities; Community Access; Personal Relationships; Money and Spending; and Work/Day Activities. It is administered in an interview format.
 3. The Guernsey Community Participation and Leisure Assessment (GCPLA), Baker (2000). The GCPLA was completed by residents only and has 53 items relating to six categories: Services; Public Transport; Indoor Leisure; Leisure, Sport & Recreation; Social; and Facilities/Amenities. Frequency of activities and support required are measured using a semi-structured interview format.
 4. Person Centred Planning Questionnaire (PCP-Q), CDS (2009). The PCP-Q was completed by residents, family members, staff and upper management. There are 7 to 11 items, depending on the version of the Questionnaire and items relate to knowledge of Person Centred Planning; what life is currently like for the person; and hopes following the Planning process. Post implementation, the items on the Questionnaire relate to how life has changed since the planning process.

Data Collection & Analysis

Baseline Data was collected by two of the Civic staff members originally trained by CDS in January/February 2010. The Person Centred Plans, (PATHs), were facilitated in March/April 2010. The first round of data collection post-planning was collected in October/November 2010 and the follow up testing was carried out in June 2011. Written consent was obtained from the participants prior to any testing.

Given the small sample size, descriptive statistics were used to analyse the quantitative data. A number of alternative analyses were also employed with regard to the qualitative components of the PCP Questionnaires.

Summary of Results

Quality of Life Questionnaire (QOL-Q)

Both houses reported a slight increase in Satisfaction since implementing the person centred plans. For both houses, Empowerment/Independence has increased since the implementation of a person-centred plan, with House 1 consistently scoring higher than House 2. House 2 has improved on all dimensions of the QOL-Q since the intervention.

Social Belonging/Community Integration is consistently the lowest scored subscale across the time intervals. Interestingly, while Social Belonging/Community Integration has declined for House 1, Empowerment/Independence has increased. This may suggest that as people become more independent and empowered, their sense of social belonging decreases.

Overall, for House 2 the average total quality of life scores have increased significantly since the implementation of the person-centred plan from 59 to 76. This increase takes into account the return to work of one of the residents who scored very highly on Competence/Productivity. House 1 demonstrated an increase in quality of life after the implementation of the person centred plan (from 87 to 97); however at follow up this score had fallen to 83.

The Choice Questionnaire

Findings from The Choice Questionnaire indicate that the residents have a moderate degree of choice in their lives, with House 1 generally scoring higher on each individual subscale and in total.

The degree of choice in relation to Domestic Activities and Money & Spending has increased for both houses since the implementation of a person-centred plan. House 1 also demonstrated an increase in degree of choice in relation to Health, Social Activities, Community Access & Personal Relationships and Work/Day Activities.

Overall, this indicates the degree of choice residents have in their lives has increased somewhat since the implementation of the person-centred plan, with House 1 demonstrating a greater improvement than House 2 (Figure 1).

Interestingly, while Social Belonging/Community Integration was the lowest scored subscale on the QOL-Q, participants rated choice related to Social Activities,

Community Access & Personal Relationships relatively highly on The Choice Questionnaire.

The Guernsey Community Participation and Leisure Assessment (GCPLA)

Results from the GCPLA indicate that the residents, on average, have a wide variety of community leisure activities and community contacts. As shown in Figure 2, both houses demonstrate a slight decline in regular activities over the time period.

Both houses showed a slight decline over time in the range of regular community activities attended. This trend is consistent with the decline in Social/Belonging/Community Integration and increase in Empowerment/Independence noted on the QOL-Q.

With regard to the level of independence or support associated with community and leisure activities, it is noted that the residents of House 2 require significantly more supervised support than residents of House 1. As would be expected, on the QOL-Q House 2 scores consistently lower than House 1 on Empowerment and Independence. All residents in House 1 demonstrate an increase in solitary activities, perhaps contributing to the decline in Social Belonging/Community Integration scores noted on the QOL-Q.

Person Centred Planning Questionnaire

From the data, it can be inferred that the residents feel positive about their person centred plans and the process exceeded their expectations as well as changed their lives for the better.

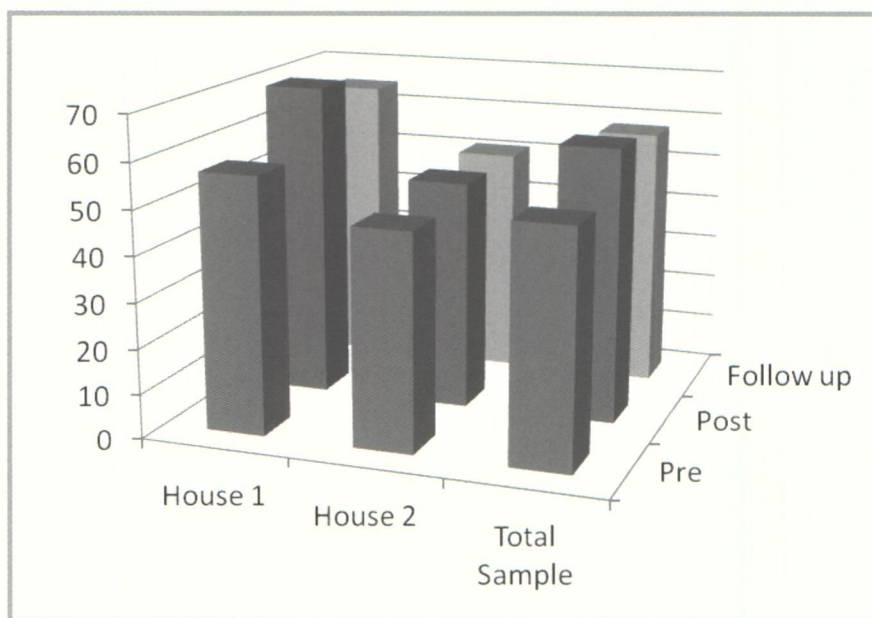


Figure 1. Mean Choice Questionnaire total scores (n=8)

Common themes to emerge from the residents' responses included: that they liked being listened to; and that achieving goals and talking about what they really want to do were things they liked best about the process.

Residents were asked about the ways in which their life had changed following the person centred plan, sample responses include:

- I have returned to work and am going a lot more.
- I've moved out on my own. I'm moving towards living on my own, independently (outside of Civic). I decide which staff will work with me now. I have a lot of choice now in my life (like when I can watch TV and what programs).
- I went on holidays and I'll move house.
- My life is good.

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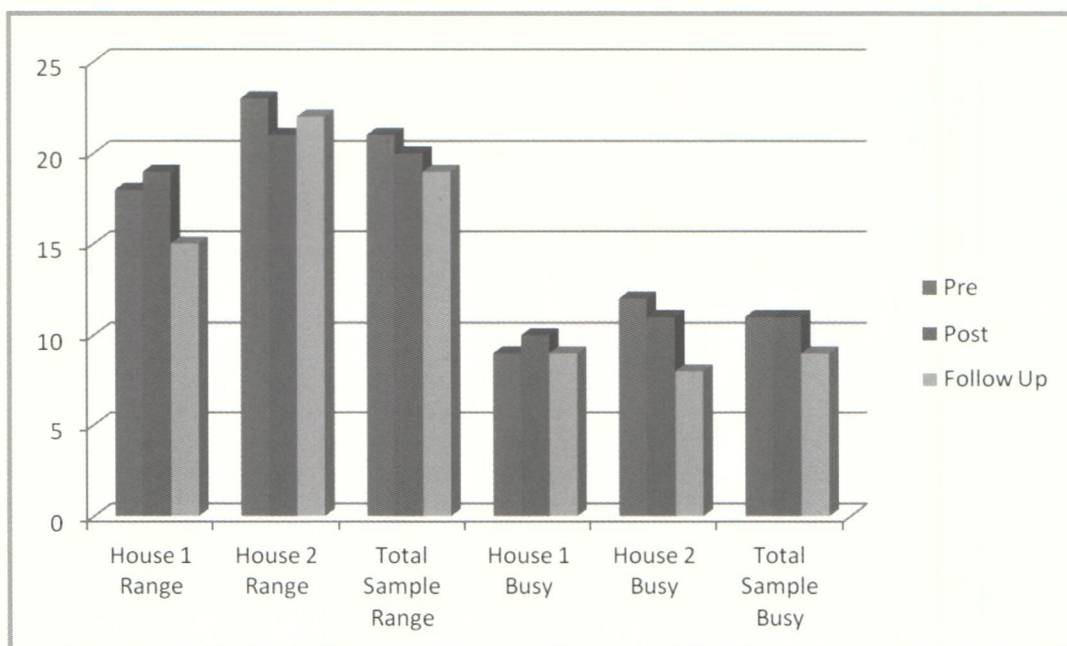


Figure 2. Mean range (regular activities) and busy (very frequent activities) scores for the GCPLA shown by house (n=8)

... Person Centred Planning

continued from page 5

Similarly, the qualitative responses gathered from family members were positive and supportive. Family members commented that their relative's life had, they believed, changed and emerging themes included: independence gained; more involvement in life; things are being followed up; needs are being met.

Responses from staff and upper management were positive in regard to how they perceive the residents' lives had changed. Comments included:

- Questions have finally been asked in a very positive way and the person feels they can answer honestly and areas of the person's life have been opened.
As a staff member, I have found out so much more about them.
- He is more passionate about his life.
- Relationships have improved.

Staff were later asked 'What have you learnt, and what have you tried that's different? The themes of the responses were: to listen and to let the person have their say without interruption; to slow down; have tried to encourage more awareness of his body language and meaning; and have changed our way of communicating to encourage his vocalising his choices.

Finally, staff were asked whether they would recommend having a person centred plan to other people, and why? All staff at both time intervals responded that yes, they would. Some reasons offered were:

- It brings out what is important to the person, and every person is different.
- It is constantly fresh. I refer back to it all the time. We do this together to keep on task.
- It makes you try things differently – to look at things in a different way.

In summary, the findings of this pilot study indicate that since engaging in the person centred planning process, the residents of Civic are happier with their lives, which appear to have changed for the better. This study had implications for residents, family members, staff and Civic as an organisation. The residents have experienced a greater degree of choice in their lives since the person centred plans were implemented. Residents made decisions about living arrangements, were empowered in taking positive actions independently and reconnected with their families. Family members and staff were also positive about their involvement in the process and the changes seen in the residents.

Staff additionally experienced a shift in the way they view their roles, a deeper level of engagement with the residents, a greater understanding of their quality of life and a strengthening of team cohesion. For Civic as an organisation, there was clarification as to what Civic can realistically provide and a broadened view of what others can provide (e.g., the community).

In light of the research findings, some recommendations have been made:

1. It appears as though there is a potential interaction between increasing empowerment and independence and a decline in sense of social belonging and community participation. The experience of social inclusion could be investigated further as the data show this area still needs development.
2. The small sample size requires the results be interpreted with caution. A greater number of participants would lead to more robust and generalisable findings. Although we were unable to conduct statistical analyses we can determine it is worthwhile to proceed with a project of a larger nature.
3. Finally, a case study approach could be used to explore and understand the lived everyday experiences of the residents of Civic and to identify the facilitators of and barriers to good person-centred practice in the group home settings. This approach could highlight the differences between the houses, which may account for the variation on the battery of tests in the current study.

To conclude, person centredness is more than planning, it is a way of thinking. As such, staff have needed to challenge their original thinking in terms of the type and quality of support they have been providing. They have needed to adapt to a change in approach to their work. From the comments made by staff, although this process is challenging, it is also rewarding. The results of this study indicate that adopting a person centred approach at Civic has the potential to improve the lives of the residents and family members as well as strengthening team cohesion among staff.

References

available upon request ●

To Beg or to Choose: you decide

46th Annual ASID Conference Report

held 9 to 11 November
Adelaide South Australia



The seafront Stamford Grand Hotel in the beautiful beachside suburb of Glenelg was selected by the organising committee as the venue for the 46th Annual ASSID Conference. With the Convention on the Rights of Persons with Disabilities and the Productivity Commission Report on Disability Care and Support the title of the conference was; **To Beg or to Choose: you decide** to reflect the emerging changes occurring both nationally and internationally in the disability arena.

Right from the onset we wanted to ensure that self-advocates were welcome and included in the conference both as presenters and active participants. As a result we began the conference with Professor Christine Bigby's key note address **Symbolic, tokenistic or value added: doing inclusive research with people with intellectual disability**. Christine's co presenters included people with an intellectual disability who are involved in a research project with Christine. Another key note speaker was David Corner a Self Advocate from New Zealand who presented a humorous, entertaining and inspiring paper titled; **Empowering self-advocates to understand the CRPD (Convention on the Rights of Persons with Disabilities)**. Having a conference sub-committee of self-advocates guiding and educating the Conference Organizing Committee was most beneficial. Students from Flinders University Disability Studies Program assisted as buddies and supporters for any delegates requiring assistance and self-advocates reported this was most helpful and preferable to paid carers.

The conference brought together three international key note speakers and a diverse group of people from Australia and New Zealand, including researchers, individuals living with a disability and their families, service providers and distinguished experts in the field of intellectual disability and created a unique opportunity to learn and to network. In total there were 367 participants in the conference.

The themes of the conference included:

- Human rights/self-determination
- Self-advocacy
- Person centred practice
- Individualised funding
- Children and families.

There were many papers related to person centred practice and Active Support indicating a gradual change in practise in the sector. However there were surprisingly few papers related to individualised funding and this appears to be because the research is not ready with many trial projects in operation as service providers are learning new way of working. I personally look forward to learning from the anticipated research on individualised funding at the 2012 Conference in New Zealand.

It is an exciting time in disability as we are on the cusp of great change and as change transpires it is imperative that research continues to drive and direct our practice. The annual ASID Conference provides an excellent opportunity to learn and debate. ●



Richard O'Loughlin, John Della Bosca and Denice Wharldall, (Denice was the conference convenor, Richard the ASID president and John was a keynote speaker)

More photos on front cover.

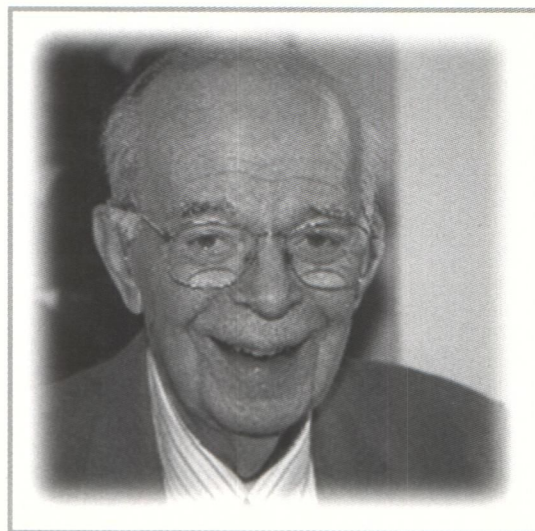
Obituary

Professor Alan Clarke

CBE, PhD, DSc, F.IASSID, FBPS

from Roy Brown

PhD, F.IASSID January 2012



It was with considerable sadness that I, along with many others, heard of Alan Clarke's death. He passed away peacefully aged 89 years in December (2011). For some months he had lost much of his speech following a stroke, which must have been extraordinarily frustrating as he had been a superb communicator in lecture, discussion and everyday life.

Members of IASSID have reason to be very grateful to him, as Alan was a member of the international founding group of IASSMD, later IASSID. The London conference on the scientific study of mental deficiency, for which he worked strenuously, took place in 1960. Alan Clarke representing the British Psychological Society, along with Harvey Stevens of the AAMD (Now AAIDD), and Alexander Shapiro of the MD section of the Medico-Psychological Association (Now the Royal College of Psychiatrists) set up the conference, which was the first ever multidisciplinary international meeting on mental deficiency. This led to a permanent body at the Copenhagen conference in 1964 now known as The International Association for the Scientific Study of Intellectual Disability.

As the first Secretary to the organisation Alan did much to steer the Association through its initial years and later became President. In more recent years he continued to take great interest in the Association as Honorary President and regularly asked for updates and commented on its activities. Although many of the younger members of IASSID may not have known Alan well they will be familiar with The Alan and Ann Clarke Keynote Lecture at each congress meeting, which brings to members cutting edge research and ideas from prominent researchers.

Alan studied Psychology at Reading University after completing military service. I remember him telling me that he was not sure what to do at that time and his brother-in-law, Dr Monte Shapiro, who was based at the Institute of Psychiatry, Denmark Hill, London, suggested that psychology was interesting. So he decided to apply to Reading University where he met his wife-to-be Ann, which resulted in a family, and professional relationship that was to have a major impact on

psychology and even more fundamentally the field of intellectual disability (now learning disabilities, UK).

Most will know of their research in the 1950s onwards that looked into the cognitive performance of people with intellectual disabilities, then called mental deficiency. Their many research articles caused a major stir because they questioned the notion of fixed IQ, dealt with the issue of pseudo feeble-mindedness (i.e. false negatives on original testing) and demonstrated that people from adverse and deprived backgrounds could recover with major increases in IQ in their late teens and twenties. They had done their homework well as they dealt with the slings and arrows which would follow publication. Their research design was rigorous with independent assessors and independent and blind prediction and also an estimate of practice effects for repeated measures.

This and other work resulted in the publication of "Mental Deficiency: The Changing Outlook" in 1958, which was the time of my introduction to the Clarkes as I was on an internship at the Manor Hospital, Epsom. I was given the job of proof reading the galleys. What an enlightening experience! The book ran into several editions and had impact around the world. The original edition read like a review of leaders in the field of intellectual disability at the time, which, in Britain in particular, was undergoing major changes that were to a considerable degree because of their efforts, and those of their colleagues including Herbert Gunzburg, Neil O'Connor, Jack Tizard, and Elspeth Stevens.

Several later editions of the book came out, each expanding in range as changes in mental deficiency took place. I still meet people who believe these were the golden days of the field in Britain for, as Alan said, the end of the second world war created an upbeat feeling and many knew of the work of people with mild intellectual disabilities during the war years working on road repair and such. I remember that overseas visitors to the Manor would stop and ask me why so many changes in the field of mental deficiency had taken place in England. The answer, to some considerable degree, was because of the work and

continued page 8

workers who wrote this book. Alan and his values were part of a zeitgeist where change was in the air.

For Alan theory and practice went hand in hand and this was the subject of his Presidential address to the Association (Clarke, 1977). Alan was both a scientist and a humanitarian and this blend led to a concern for people with intellectual disabilities, their conditions and their treatment. In their Psychology Department at the Manor Hospital, Alan and Ann carried out not just research but facilitation of young people with intellectual disability, many of whom came from very adverse backgrounds.

After my internship, Alan invited me to become a psychologist in their department, where I experienced kind and wise support from both Alan and Ann. Alan, as a leader and mentor, had a dramatic effect on my own career. But then that was the nature of the man! I have met many colleagues and students who were grateful for his sincere interest in them and for his kind but well structured advice.

After leaving the Manor Hospital Alan became Professor and Head of the Psychology Department at the University of Hull and later Pro-Vice Chancellor. He was President of the British Psychological Society (1977-78) and was often involved in government committees where his reputation and skills moved things along. He was awarded a richly deserved C.B.E. (Commander of the British Empire).

I cannot but think of Alan other than jointly with Ann. Together Alan and Ann were a remarkable team. They continued to publish over the years and after retirement produced major books, which dealt with important, and challenging issues such as why some people survive against all odds. Their book *Human Resilience: A Fifty Year Quest* (2003) is a living tribute to their joint work as it brings together a collection of their research writing and clinical experience over the years- their quest has laid the ground for much future work- and the quest goes on!

Alan will be remembered as a man who blended research, theory, and humanitarian concern with day-to-day support and care. He will be dearly missed by

Ann, his 2 sons Bob and Peter and their families, as well as by a wide range of friends and colleagues all of whom owe him so much.

References

Clarke, A.D.B. (1977). Presidential address: From Research to Practice . In P. Mittler, (Ed) *Research to Practice in Mental Retardation*, Vol 1 (p. A, 7-19). Baltimore: University Park Press.

Clarke, Ann & Clarke, Alan. (2003). *Human Resilience: A Fifty Year Quest*. London: Jessica Kingsley ●

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Queensland

by Michael Keates

The ASID Queensland committee kicked off the new year by holding their annual planning day in early January. With a predominantly new committee, this provided the opportunity to focus on the function of ASID Queensland, roles and responsibilities of committee members, working together effectively and supporting good governance.

In 2012 ASID Queensland will continue with an overarching focus on 'research to practice'. Several subcommittees have been formed, each currently progressing work to develop a local operational plan to support implementation of the national operational plan. Particular emphasis will be given to improving communication with our members and providing greater benefits for state members through access to information, support and learning opportunities. Subcommittees will feedback their work to the committee in March and will allow finalization of a state operational plan. This plan will adopt an 18 month planning and implementation cycle and support a longer range view to the goals and activities of the committee. Specific details relating to our State Conference and other local events will be published in March and will also appear on our blog site.

Finally a brief acknowledgement of the role and commitment of Warren Losberg to ASID Queensland; Warren has recently withdrawn from the committee to focus on work and personal commitments. Thanks for your support Warren and all the best with your future endeavors.

New Zealand

by Adrian Higgins

New Zealand has just held its annual face-to face meeting in Wellington. The incoming council has set its agenda for teleconferences for the year and all office holders have now been formalised with Christine Wilson taking up the position of secretary. We have two new council members in 2012 with Beverley Kohleis and Louise Mitchell being welcomed onto the council. We look forward to their contributions.

The 2011 ASID-NZ National Conference & AGM held in Rotorua was well attended with around 180 delegates attending. The high number of delegates meant that the conference yet again ran at a profit which allows us the resources to look for ways to further ASIDs strategic goals.

With New Zealand hosting this year's Australasian conference a large part of the meeting given over to tasks and responsibilities for Council members.

We also meet with the conference organisers Paardekooper & Associates. The council expressed its appreciation to the Conference Convenor, Sharon Brandford and her team for the work they have carried out to date particularly the securing of the major sponsors. The web site is now operational and can be accessed from the ASID web site or directly at <http://www.asid-2012.org.nz/>. We would encourage all members to visit the site. We are confident that we are meeting our planning timelines and that all preparations are well in hand.

The NZ council has looked at new ways to promote ASID in its region. We are trialling a means of prompting emerging young practitioners in the sector by holding a seminar in the Dunedin where three selected presentations from the NZ National conference will be re-presented with more time allowed for presentation, interaction and comments. The focus will be on Research to Practice. Our intention is to make this an annual event and host these seminars in both the North and South Islands.

The council is also exploring the possibility of making an ASID-NZ prize available to selected university departments for research that is consistent with the strategic goals of ASID. Strengthening our links with academic institutions will be a focus for 2012.

NSW & ACT

By Tina Purdon

We welcome all NSW and ACT members to another busy year for your Regional Committee. Happy New Year also to our ASID colleagues across Australia and New Zealand.

It did seem when we were children, that it was a very long time between Christmas'. Nowadays it seems as if one Christmas has just passed and the next is fast approaching. 2012 promises to be no different with the first quarter nearly at an end!

Some things however seem to take ages and for many researchers, people with disability and their families and other supporters in NSW, this may be the case with progression to a true person centred focus in service provision.

The sector was excited when the NSW State Government introduced Stronger Together – a 10 year plan commencing in 2006, promising major reforms and service expansions. In 2011, we were halfway through the Plan and for many individuals little had changed. However

with the introduction of the Stronger Together Two the focus on developing the person centred approach strengthened, supported by a commitment that “ people with disabilities will be the key determiners of how support resources are used”.

NSW Family and Community Services
– Ageing, Disability and Home Care, Stronger

Together: A new direction for disability services in NSW 2006-2016

This year a number of key drivers in the NSW disability sector will be changing. In particular it is envisaged the increased rollout of self managed funding packages will impact on families, service providers and employees in the sector, as well as the person receiving the funding. Conversations with families and carers indicate that there is nerves and apprehension about how funds can be managed, if they will be able to do this successfully and if they will have the time. Many with existing self managed packages are now feeling the ongoing pressure of responsibility for the funding and implementing what is best for the individual from what is available in their local community. There may be disparities here between metropolitan and regional areas. Service providers and employees are wondering what the future will look like for them and the programs they currently offer. The common sentiment is that everyone is excited about the prospect that disability services in NSW will be revolutionised and reborn into the type of support that people actually want and choose and that most Service Providers aim for in their Vision and Mission Statements, but are currently constrained in achieving.

In the context of this energy, enthusiasm and change, it was easy this year for the Committee to select the theme for our 2012 Regional Conference on Friday 17th August. We are very pleased to announce that John Della Bosca will be the keynote speaker at this event.

*Through the Looking Glass –
putting the talk, research and planning into action!*

We would like to invite our ASID colleagues to consider submitting an abstract for presentation at this Conference. It is recognised that we can learn much from other Regions as well as within our own and hope that many will take this opportunity to share their achievements and their research. Please consider the following subthemes and look out for the Call for Abstracts which will be placed on the ASID website and emailed to NSW / ACT members shortly.

- INNOVATION – Sharing great ideas that are out there and working. How are people changing things by putting research into practice?
- NEW PERSPECTIVES – What is being planned? How are stakeholders responding to change? How will research support us to look at things differently?
- SYSTEMS CHANGE – What will be different and what impact may this have? Sharing things that have already changed and managing the impact of this change.
- TECHNOLOGY – How can the use of technology assist us to meet the expectations of the future? How is technology being used now? What is the relevant research which supports the embracing of technology in supporting people with disabilities? Can technology assist the support of people in remote or isolated settings?
- NAVIGATING NEW FUNDING AND SUPPORT STRUCTURES – How will people know what is around, who is doing what and how they can get what they are looking for? What are the lessons already learnt that will help us avoid pitfalls?

Plans are also underway for an event on the 4th June. In partnership with Northcott Disability Services we will co-convening a round table event “Ethical Research in Service Delivery”, inviting sector agencies, funders and university research representatives. The aim of the event is to ensure everyone understands their ethical responsibilities for the conduct and public dissemination of research conducted in a given agency. We'll keep you posted on the outcomes.

Further details for this event will be distributed in the near future. People with enquiries are invited to contact Michele Weise on 9890 0100, or send her an email michele.weise@northcott.com.au

It has been an energetic and busy start to 2012 and we look forward with enthusiasm to achieving the goals we have set for ourselves!

We again invite contact from ASID members or persons in ACT, interested in finding out about joining the Regional Committee and representing the views of ACT. Please contact lindaward@sunshinehome.net.au with your interest or to just make enquiries.

Western Australia

by Chris Yates

The year has commenced on a busy note for ASID WA!

We have two sundowners planned which will provide opportunities to bring together people with an interest in the field of intellectual disability to share a mix of research and experience.

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The first sundowner on February 21st will focus on an independent evaluation of the Positive Behaviour Teams operating in Western Australia which has been completed by Dr Keith McVilly, Associate Professor at Deakin University in Melbourne. Keith will present the report with an opportunity for questions and discussion afterwards.

Then, just a week later on February 28th we will host another sundowner and this time our keynote guest will be Professor Eric Emerson. The topic is 'Better health outcomes for people with a disability' and we will focus on the urgent need to improve the health and well being of people with a disability. This sundowner will be presented in a panel format with input from Professor Emerson, advocates, family members and researchers followed up by questions and discussion from the audience.

Looking further ahead the Regional Council has commenced discussions with partner organisations for other events throughout the year; we have already started thinking about this year's conference to be held in September and we also have a longer view in mind and are already beginning to think of the Australasian conference in 2014. Guiding all of our thinking is our strategic plan which has gone out to all members in final draft format for comment and we are collating responses at the moment.

So, we are off to a flying start and look forward to reporting back to members on the forthcoming activities and seeking input into those events which are still to come.

Tasmania

by Ben Crothers

The Tasmanian Regional Council's 2011 Annual General Meeting has resulted in a number of membership changes. The council would like to thank outgoing council members, Darryleen Wiggins, Barb Olsen, David Treanor, and Rick Baxter for their work spanning many years in total. The council would further like to sadly say farewell and thanks to Libby Richardson for her extensive contribution to the organisation, and wish her luck into the future.

The current regional council membership is: Ben Crothers (President/Board Member), Lena Mitchell (Vice-President), Ian Hopkins (Secretary), Craig Jones (Treasurer/Board Member), Nadia Ollington, Tanya Petrie, and Mary Mallett. Planning is well under way for the year's events and activities, including our inaugural quiz night.

There are currently a number of vacancies on the Tasmanian Regional Council, and we encourage local members to consider expressing interest in a position.

In other sector news, this July in Hobart, the Tasmanian chapter of the Australian Association of Special Education (AASE) will be hosting the AASE National Conference in partnership with the Tasmanian Principal's Association (TPA). The conference is titled "Ethical Leadership for All" and the choice of keynote speakers indicates a quality professional learning experience for those working with Intellectual Disability in an educational setting. More information is available from the AASE website.

South Australia

by Denice Wharldall

With the Australasian Conference now over the SA team will be focusing on local events for members and plan to have a workshop on Individualised Funding with a focus on showcasing the results of evaluations of local Individualised Funding Projects. More information will be available shortly.

The Active Support Train the Trainer Workshop held last year was very successful and greatly assisted many service providers begin the journey of implementing Active Support. South Australia has an Active Support Community of Practise and new members are most welcome. Please email Val Crowther at Cara for more information vcrowther@cara.org.au

ASID SA welcomes the South Australian Government recently released report titled Strong Voices, A Blueprint to Enhance Life and Claim the Rights of People with Disability in South Australia (2012-2020). Strong Voices contains 34 recommendations to the Government across 6 key areas of reform:

1. Creating Accessible and Inclusive Communities
2. Providing Choice, Taking Control
3. Strengthening Rights, Protection, Advocacy and Safeguards
4. Investing Early
5. Diversifying Housing Choices
6. Shaping Accessible and Inclusive Services

The Minister has approved seventeen of the recommendations. For a copy of the report please go to www.socialinclusion.sa.gov.au and follow the link to the report.

Victoria No report ●

Identifying factors that impede training and service development for mental health of children and adolescents with intellectual disability

Experiences from the development of a curriculum for inter-disciplinary training

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Introduction

The mental health of children and adolescents with intellectual disability (ID) is a public concern. It is recognised that 30-50% of children and adolescents with ID have significant mental health problems. It is also found that the mental health of children and adolescents with ID constitutes 14% of mental health burden of all children (Emerson & Hatton 2007). 25% of CAMHS services capacity in UK is for ID and/or Autism. These mental health problems and the concomitant burden affect the quality of life of these young people and their families. They lead to 2-3 times greater financial burden for care, treatment & education as well as reduced income capacity. Over half of carers (59%) experienced a decline in physical health & two-thirds felt that their mental & emotional health was affected with depression, anxiety or stress (Cummins et al 2005). This is in the context of no designated mental health service for mental health and ID in Australia. The question of what impedes the training and service development for mental health of children and adolescents with ID arose during the development of a curriculum for inter-disciplinary training when we became aware there has been no previous textbook covering this area of multidisciplinary expertise (Dossetor, White and Watson, 2011)?

Method

This paper is based from discourse with colleagues and trainees which identified some of the differences of mental health for children and adolescents with ID from mainstream mental health. This was in the context of developing the Training Curriculum Project, which is a 2 day interdisciplinary curriculum. This project had 3 years funding from 3rd National Mental Health Plan and Aging, Disability and Home Care, NSW Human Services (ADHC) for a project manager (DW) and was a partnership project between the Department

of Psychological Medicine at the Children's Hospital at Westmead with Statewide Behaviour Intervention Service (SBIS) ADHC (LW). Observations came from: a literature review; clinical experience of what works in a tertiary multidisciplinary multi-agency clinic; areas of demand for training from SBIS; a stakeholders' survey of areas of intervention-focused learning; evaluations and 3 month outcomes on workshops; commissioning 28 chapters which were independently reviewed for the textbook. In 2009/10 we provided 4 2-day workshops to >500 clinicians and the evaluation and feedback from the curriculum was positive and clinicians reported at three months that it had made a difference to their clinical practices.

The Findings

The findings are presented under 8 headings below.

1. Ambiguous terminology

There is a lack of an internationally accepted language: The term "Mental Retardation" is still used in America. The term "Learning Disability" is used in UK, whereas this term is used in America is for Specific learning problems. In Australia you are never sure what group of problems this term is being used for. The term "Dual diagnosis" refers to ID and mental health problems in USA and UK, but mental health and drug and alcohol problems in Australia. There is widespread obfuscation of communication through agency/discipline specific jargon; we readily identified 125 abbreviations in common usage and no workshop attendee could accurately interpret all. One is forced to conclude that there is no evident common language.

2. Dichotomous and Divisive Concepts

Challenging Behaviours is a concept of poor social adaptation that implies an environmentally caused or maintained problem and needs a linear behavioural approach to intervention. This is the *continued page 14*

primary model used by Disability Services. Psychiatric Disorder is an alternative concept that implies a disease model of poor social adaptation identified by syndromal clustering of features and requiring the expertise of mental health services. Yet both models acknowledge bio psycho social factors. Some practitioners only work with one of these concepts although the research indicates that they frequently co-occur. Professional discrimination persists against ID as illustrated by the comment: "if the patient can't talk then they can't have a mental disorder". Most condition specific research is limited to Mild ID and there is little agreement on how mental disturbances are different in the earlier stages of mental development.

3. Problems of diagnosis of mental health problems in adult with ID

A mental health problem is defined as "*a diagnosable illness that significantly interferes with an individual's cognitive, emotional, or social abilities.*" Experts assert that generally it has been recognised that those "with ID have the full spectrum of mental illness, but usual diagnostic criteria are difficult to apply".

Methodical approaches to diagnosis are a recent development. The textbook of diagnosis of mental disorders in persons with an ID (DM-ID) was published in 2007. This diagnostic and statistical manual of mental disorder for people with ID was developed by an international, predominantly American, expert group. Each chapter reviews of the strength of the evidence supporting each diagnosis and the adaptations of diagnostic criteria for persons with ID. However the levels of Cochrane based scientific evidence are generally poor, mainly based on cohort studies and expert opinion. Nonetheless this manual of diagnosis gives people with ID entitlement to MH services. Its clinical usefulness was evaluated in 2006 with a field trial 900 patients, 80 clinicians from 11 countries. This reported that the DM-ID was user friendly and more specific than the DSM-IV-TR (text revision 2004).

The main alternative is the DC-LD (Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation) which was developed in UK (2001, Royal College of Psychiatrists). This provides a "consensus of current practice" for adults with moderate to profound ID leading to ICD10 diagnoses. Their approach is slightly different emphasising that "sometimes it is not the criteria that need alteration but a different method of eliciting the necessary information".

Nonetheless both diagnostic manuals identify a number of special problems of eliciting phenomenology in ID.

1. Firstly it is not possible to elicit subjective mental phenomena reliably < 7 years or an IQ <45. It is little surprise that debate still surrounds the age at which depression or psychosis can be identified in children.
2. People with ID have difficulty articulating abstract or global concepts eg depressed mood, because of limited cognitive and verbal skills.
3. They are more likely to give answers to please the interviewer.
4. They may be subject to intellectual distortion for example saying "yes" to "hearing voices", without understanding the implication of question.
5. "Diagnostic overshadowing" is the failure to identify co-morbid psychiatric disorder attributing disturbance to the underlying intellectual disability.
6. This has to be distinguished from baseline exaggeration or intensification of existing maladaptive behaviour. Examples include an increase in self injurious behaviour under a time of stress. A significant stressor can be an anniversary of a loss that carers may not identify, or a change of a teacher or other staff, or a classroom or accommodation or of family visits.
7. Conversely stress on coping with a lack of cognitive reserve leads to disintegration, disorganisation or psychotic behaviour implying that such a major stress response does not constitute a mental illness (although adjustment disorders are part of the diagnostic manual).
8. Delusions and hallucinations are frequently very difficult to distinguish from a range of normal developmental phenomena such as concrete thinking, pretend friends, and stereotypic thinking and imagination, especially in ASD.
9. Irritability including explosive anger may be the most common problem of challenging behaviour but is also associated with depression and mania.

Indeed it is concluded that families and professionals alike are at risk of diagnosing serious psychiatric disorder where none exists. Conversely the literature also illustrates that non specialised doctors (GPs) fail to identify mental disorder eg depression in this population. Further there is no advice on how to tackle these special problems, apart from consulting "an expert".

4. Comparing diagnoses in America and UK

Tsiouris and colleagues (2008) probably did the largest study of 4468 clients, 34 of whom were in out of home residential settings, and found psychiatric disorder in 60%. The main DSMIV psychiatric diagnoses in order of frequency:

- Impulse Disorder 21%
- Anxiety Disorder 19%
- Schizophrenia and other psychoses 18%
- Depression 14%
- Bipolar Disorder 12%
- Obsessional Compulsive Disorder 11%
- Personality Disorder 8%
- Sleeping Disorder 4%
- Eating Disorder 3%
- Tourettes 2%

Almost as interesting was the absence of many other diagnoses described as of high prevalence in DM-ID such as Adjustment Disorders; Post traumatic Stress Disorders; Substance-related disorders; Sexual & Gender Identity Disorder; Dementia; Mental Disorders due to a General Medical Condition Nos. None of the childhood disorders that are also recognised to continue into adulthood were identified such as Learning Disorders; Motor Skills Disorders; Elimination Disorders; Pervasive Developmental Disorders; ADHD and Disruptive behaviour disorders; Somatoform & factitious disorders; Other Disorders of infancy, children and adolescents eg Attachment Disorders and Stereotypic movement disorders incl. self injurious behaviour; Behavioural Phenotype of Genetic Disorders.

The Epidemiological study in Scotland by Cooper and colleagues (2007) was of 1023 adults over 16yrs with mild, mod or severe ID. The PAS-ADD checklist, a screening questionnaire, was used to screen the population and the psychiatric diagnosis was made on the PAS-ADD 10 (The psychiatric assessment schedule for adults with a developmental disability) which relies on a key informant to identify and rate symptoms and produces diagnoses using algorithms (Costello et al, 1997).

The types of ICD10 Psychiatric Disorder were:

- Psychotic Disorder 4.4%
- Affective Disorder 6.6%
- Autistic Spectrum Disorder 7.5%
- Anxiety Disorder 3.8%

- Organic Disorder 2.2%
- Pica 2%
- Hyperkinetic Disorder 1.7%
- Personality Disorder 1%
- Alcohol/substance abuse 1%
- Obsessional Compulsive Disorder 0.7%
- Sleep Disorder 0.6%
- Other mental ill-health 1.4%

Why is there such disparity of diagnoses identified and of their frequencies? The American study is of service users, where the UK study is more epidemiologically representative. It is evident that research diagnostic tools identify lower levels of disorder than specialist clinicians seeking to understand disturbance. However one is still left to conclude that there is a lack of uniformity of diagnostic concepts and of thresholds of diagnosis. It suggests a lack of diagnostic reliability at least across an international community of clinicians. Indeed behind these discrepancies lie different diagnostic and schools of psychiatric thought. This is reminiscent of the 1980s when ADHD was diagnosed at rates ten times that in UK, before international collaboration clarified the concept and the dimension of severity which is dealt with differently in the different diagnostic systems. Evidently the research process to establish an international consensus is yet to be investigated and funded.

5. The Need for Special Diagnostic Skills

Part of the problem is the need for special diagnostic skills to make a psychiatric diagnosis in people with intellectual disability, as has been illustrated in research on identifying depression in ID.

For example Hurley (2008) found that in a retrospective review in a clinic population that most patients with ID and depression did not meet the required number of diagnostic criteria for DSM or DM-ID. Patients with ID and depression do not complain of depressed thoughts. They still had depressed mood, sadness, crying, anhedonia and withdrawal which distinguished from anxiety or bipolar disorder. Few reported suicidality.

Torr and colleagues (2008) in an Australian study compared GPs' and long term paid carers' capacity for identifying features of depression in patients with ID having a routine assessment. These findings were then compared with subsequent assessment with a comprehensive specialist psychiatric assessment. The study used a 53 item checklist for

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depression and factor analysis identified the consistent features of depression: depressed mood (6 items), loss of interest (5 items), loss of social interaction and communication (8 items). Carers identified the features of depression but GPs failed, even with the carers present. Depressed thinking was not a reliable feature of depression reflecting limited communication skills. GPs focussed more on sleep, appetite, weight control and general functioning. In this cohort, expert opinion found that 30% had depression but 25% had a Pervasive Developmental Disorder.

GPs are normally viewed as the gate keepers to specialist services, including mental health. Such evidence indicates that access to mental health services for people with ID is disadvantaged by the lack of workforce training. Both GPs & general psychiatrist will fail to provide the same level of case identification as a psychiatrist with special experience in intellectual disability. There is a need for further education and support for the recognition of subspecialty psychiatry skills in ID.

6. Differences in defining mental health problems in children and adolescents with ID

Child and adolescent mental health defines a psychiatric disorder *as any disturbance of behaviour or emotions sufficient to cause significant impairment to the child or those caring for them*. The longitudinal study of young people with ID indicates 40% have a severe mental health disorder (Einfeld & Tonge, 1996). The Developmental Behaviour Checklist (DBC) measures the range and severity of disturbance but doesn't translate to psychiatric disorders. Although it is observed that psychiatric disorders in ID create greater problems for their families, there is no study that has quantified the additional impairment of Psych Disorder in ID versus that of ID alone. In children and adolescents with ID a clinician may ascribe disturbed behaviour to a Mental Illness, a Mental Disorder, a Developmental Disorder, a Challenging Behaviour or Behaviour Problem. However the use of these labels is substantially a subjective determination affected by profession, employing agency and different theoretical models.

Mental health services, including child and adolescent mental health services have progressively prioritised their business to **severe mental illness** and the provision of **emergency intervention services for acute mental disorder**. The concomitant community message that "mental health is everyone's business" suggests all

child orientated services have to understand and manage mental health problems.

Aggression is the most common community based childhood problem but research finds that by the age of 10 years such behaviour is an entrenched and chronic problem that generally doesn't improve in psychiatric in-patient units. Accordingly most conditions are best treated in the community which requires shared responsibility between families, neighbourhoods and all government departments. Too often the Juvenile Justice system becomes the default service for a lack of community based mental health services.

7. Mental health problems in children and adolescents with ID are different and need different approaches, eg ADHD and other developmental disorders.

The way mental health problems in children and adolescents with ID present are different to those with average IQ. For example 30-50% of children with severe ID have ASD (compared 1% in the average population). The significance and meaning or validity of a diagnosis may be different for different levels of ID. Using ADHD as an example, Anstel and colleagues (2006) reviewed ADHD in Mild ID. Although they confirmed the diagnosis could be made reliably, there were differences in the predictive validity of this diagnosis. The differences included: the prevalence is 30%, with equal frequency in girls as boys, stronger factors of family functioning, and a stronger association with depression and social impairment. Further standard drug treatment is not as effective and patients are more prone to side effects.

In contrast for ADHD in severe ID there is a lack of research for reliability and validity, although it can be observed that these cases are more affected by general neurobiological factors as well as the polygenic processes considered important in ADHD of average IQ.

Further ADHD is associated with other developmental disorders. Examples include:

- ADHD and Developmental Coordination Disorder each occur in community studies at a rate of 7%, but co-occur in 50%.
- ADHD is found in 50% of teenagers with ID plus autism vs 15% with ID without autism (Bradley 2006)
- ADHD is found in 78% of PDD in clinic population (Lee & Ousley 2006)
- Genetic studies confirm linkage between ID and Autism indicating a commonality of development processes behind both.

ADHD is particularly high in behavioural phenotypes:

- Smith Magenis Syndrome 90%, Fragile X 75%, Williams Syndrome 65%, Charge Syndrome 50%, Neurofibromatosis 50%, Velo cardio facial syndrome 43%, Cornelia de Lange's Syndrome 40%, Soto's Syndrome 38%, Tuberosa Sclerosis 35% and Turners Syndrome 24%.
- In Fetal alcohol syndrome ADHD is found in 49%, ID in 55%, learning disorders 46%, ODD 41%, anger problems, mood disorders and sleep disorders in 50%.

Taking these observations into account suggests that ADHD in ID represents the specific problems of developing coherence & efficiency of consciousness, rather than a specific disease process. It may still be helpful to identify co-morbid ADHD particularly based on the evidence and experience of the reduction of impairment from drug treatment.

In conclusion Developmental Disorders have high risks of co-occurrence, which are highly genetic and may all relate to problems of developing neural complexity.

8. Other problems in mental health for children and adolescents with ID

In the provision of mental health services for children and adolescent with ID there are a number of other problems. These include:

- Different models for understanding mental health are used by different disciplines and agencies.
- Some agencies are individual centred and lack of family centred approach.
- There is a lack of clinicians with evidence-based practice expertise, and experience in both mental health and ID.
- There is an increased association with complex medical problems.
- There is a lack of recognition of the range of the disciplines and agencies required to be optimally involved.
- There is a lack of inter agency collaboration with service cost shifting.
- There is a lack of service structure for more severe problems.
- There is a lack of attention to Prevention Promotion and Early Intervention
- There is limited empirical evidence on the contributions to be gained from occupational therapy, physiotherapy, speech therapy, psycho-pharmaco

therapy, family therapy and systemic practice which are all considered part of comprehensive treatment. (The best evidence is for parent training and behaviour therapy.)

As a result, families experience a rotating front door of inexperienced community clinicians. Problems escalate without effective intervention. This provides some explanation to why parental murder/suicide ideation is such a frequent presentation in the families of children and adolescents with mental health problems and ID.

Solutions for the mental health problems for children and adolescents with ID

Our educational research identified the need for a coherent curriculum for mental health for children and adolescents with ID. This included:

- A framework that is applicable for all professionals working with children and adolescents with ID
- In the context of the family life cycle for a child with ID
- With a focus on the quality of life for child with ID and family
- Within a developmental framework that
 - informs multidimensional assessment
 - provides a context for understanding behaviour
 - and an alternative approach for understanding developmental psychiatric disorders eg ADHD and ASD
- That assumes multi causal mechanisms to disturbance and disorder
- Puts an emphasis on multimodal skill building/positive psychology
- Requires multidisciplinary/multiagency collaboration

In practice a specialist mental health service for children and adolescents with ID needs a multidisciplinary/multi-agency team that works closely together. Although the team uses a multi causal framework as a common language for mental health problems in ID, clinical expertise and consensus decides whether these causes may be additive, or whether one may be dominant in an individual case. There is a valuable tension between developmental models versus deconstructive (illness) models.

A Problem solving service system needs to be tiered so as to involve greater expertise with *continued page 18*

DVD Resource

Transition to Retirement

Roger J Stancliffe, Nathan J Wilson,
Nicolette Gambin, Chris Bigby,
Sue Balandin & Diane Craig

How to support older people with intellectual disability transition to retirement represents a major challenge for people with intellectual disability, their families and disability service providers. A 3-year research project led by Associate Professor Roger Stancliffe of the University of Sydney has been supporting a group of older people with intellectual disability to transition to retirement. This research is an ARC-Linkage project funded by The Australian Research Council, Australian Foundation for Disability (AFFORD), and St John of God, Accord. In conjunction with AFFORD, a DVD resource has been developed describing six individual transition-to-retirement stories.

The objective of the *Transition to Retirement* project was to support older people with a lifelong disability to experience an active and inclusive retirement. People with disability, particularly intellectual disability, are now living longer, which is very positive but presents



new challenges as these individuals approach retirement age. There is no clear policy or range of paths for people to follow to develop a retirement lifestyle. The research project offered one alternative to assist people to gradually begin to develop an active retirement lifestyle as they ease out of their full-time supported employment.

To achieve this, the research team tested a novel intervention that saw participants swap or drop one day of work a week in order to join a local mainstream community group or volunteering opportunity of their choice with support from members already in their chosen group who were trained as mentors.

Led by Roger, the research team - comprising Professor Chris Bigby and Ms Diane Craig of La Trobe University,

... inter-disciplinary training

continued from page 17

difficult to solve problems with rules of interagency collaboration. This could lead to a final common pathway of complex case conference, where clinical judgement and service management meet.

Specific Prevention, Promotion and Early Intervention approaches are needed for this population as generic mental health strategies are not applicable (CHW School-Link Needs Analysis, 2010). Some of the components should include:

- Universally available **specialist** parent training
- Emotional literacy programs in schools
- Multidisciplinary approaches to building skills

Conclusion

The scientific evidence in mental health problems in ID is still in an early stage of development. Mental

health for children and adolescents with ID is different from adult psychiatry for ID and mainstream child and adolescent psychiatry. A curriculum framework is necessary to establish a coherent service with inter-disciplinary and interagency collaboration. Specialised clinicians are positive on the impact that such services can have on the morbidity from co occurring psychiatric disorder in ID in partnership with families and child orientated agencies.

Lastly developmental psychiatry for children and adolescents with ID has much to contribute to mainstream psychiatry. After all, how can you be interested in "losing your mind" without studying the development of the mind.

This paper was presented at ASID Conference Brisbane and IASSID Conference Rome, Sept and Oct 2010.

References (available upon request) ●

upcoming events

3 - 4 May 2012	National Disability Services Conference Adelaide South Australia www.nds.org.au/events/1317948204
30 May - 2 June 2012	AusACPDM Conference Brisbane Queensland Australasian Academy of Cerebral Palsy and Developmental Medicine www.ausacpdm2012.org
9 - 14 July 2012	2012 IASSID World Congress Halifax Canada
8 - 10 Aug 2012	10th Biennial Early Childhood Intervention Australia Conference Perth, Western Australia
11 - 13 Sept 2012	Disability Studies Conference Lancaster University www.lancs.ac.uk/disabilityconference/
1 - 2 Nov 2012	23rd PANDDA 2012 Conference venue to be confirmed Professional Association of Nurses in Developmental Disability Australia. www.pandda.com
7 - 9 Nov 2012	47th ASID annual conference Wellington New Zealand www.asid-2012.org.nz

If you want to advertise your conference in IDA's upcoming events section,
please e-mail: susan.peden@dsc.wa.gov.au

... retirement

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Professor Susan Balandin from Molde University College, Norway, and Dr Nathan Wilson of the University of Sydney, saw very positive results achieved by the participants who took part in the project. Initial findings from the research were presented at the ASID conference in Adelaide in November 2011, and the research team hope to present the overall findings at the 2012 IASSID congress being held in Halifax, Canada.

The Australian Foundation for Disability (AFFORD) received a grant from The Trust Company to make a DVD resource based on the project. The DVD entitled *'Transition to Retirement'* was formally launched by the Hon. Andrew Constance MP, NSW Minister for Ageing and Minister for Disability Services at an event hosted by AFFORD in Penrith, NSW in late November 2011. "There are over 8,600 people with a disability in NSW in supported employment and preparing for retirement can be a daunting prospect," Mr Constance said. "This new resource will help people with a disability and service providers identify opportunities and overcome barriers that can confront them when they leave the workforce."

The DVD includes the stories of six people who took part in the study. These stories provide a user-friendly and easily understood depiction of the approach that can be used by practitioners to illustrate to other

people with a disability, their families and carers, what is possible in retirement with the right level of support. *'Transition to Retirement'* also provides an excellent teaching resource on topics such as disability, ageing, retirement, volunteering and social inclusion. The DVD with a commentary from the researchers Roger Stancliffe and Nathan Wilson is available via the AFFORD website: www.afford.com.au (click on the TTR tab).

For more information about the research project contact:

Roger Stancliffe: roger.stancliffe@sydney.edu.au
Chris Bigby: c.bigby@latrobe.edu.au

For more information about the Transition to Retirement program at AFFORD contact: nicolette.gambin@afford.com.au

For more information about the background to the research project please read:

Wilson, N. J., Stancliffe, R. J., Bigby, C., Balandin, S., & Craig, D. (2010). The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability. *Journal of Intellectual & Developmental Disability*, 35(3), 211-214. doi: 10.3109/13668250.2010.481784 ●

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research to practice

Conference 2012

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