

The Centre for Developmental Disability Health Victoria*

Developing Better Health Outcomes for
People with Developmental Disability



Conference Proceedings

Combined International Roundtable of the Health Issues and Mental Health Special Interest Research Groups (SIRG) of the International Association for the Scientific Study of Intellectual Disability (IASSID) and the Annual Conference of the Australian Association of Developmental Disability Medicine (AADDM).

28-30 September 2005
Carlton Crest Hotel, Melbourne, Victoria, Australia



Organising committee

Associate Professor Robert W Davis

Mrs Faye Alphonso

Mrs Caroline Menara

Dr Donna Henderson

RACGP QA & CPD Program

This conference has been submitted to the Royal Australian College of General Practitioners for a 2-point per hour allocation in the QA & CPD Program.

Participants wishing to avail yourselves of the points for your attendance must apply by registering your name on the clip board drawn up for this purpose at the conference registration desk.

Centre for Developmental Disability Health Victoria

A joint initiative of Monash University and the University of Melbourne

Funded by Disability Services,
the Department of Human Services,
State Government of Victoria.

The Centre for Developmental Disability Health Victoria (CDDHV) is an academic unit in the School of Primary Health Care, Faculty of Medicine, Nursing and Health Sciences at Monash University. It is a joint initiative of Monash University and the University of Melbourne and is funded by Disability Services, Department of Human Services Victoria. The centre's mission is to improve health outcomes for people with developmental disabilities by enhancing the capacity of the generic service systems to meet the needs of this population.

People with developmental disability make up over two per cent of the population. On an average people with developmental disability die 20 years earlier and are 58 times more likely to die before the age of 50 than the general population. The CDDHV, established in 1998 as a result of the amalgamation of the two disability units at both universities, has been in operation for more than five years and aims to improve health outcomes through education programs for undergraduate medical students and medical practitioners, research into health issues, direct clinical services and secondary and tertiary consultations.

As an academic centre set up as a joint initiative of both Monash and Melbourne universities, we have a close working relationship with curriculum coordinators of both medical schools. We see the inclusion of Developmental Disability Medicine in the undergraduate medical curriculum as important both in providing students with opportunities to develop specific attitudes, skills and knowledge required to provide high quality medical care to this particular patient population, and in providing them with valuable generic skills. Both medical schools have recently launched new curricula and this has created opportunities for the centre to contribute new curriculum components to undergraduate medical student education in this area of medical training. Centre staff now teach at multiple year levels in both medical courses, and therefore contribute to the training of every medical graduate in Victoria.



To improve and enhance our clinical services, our new research, teaching and clinical facility was launched at the centre's administrative offices in Oakleigh last December. The new service is close to the population centre of Melbourne and the geographic centre of Victoria. It is adjacent to Oakleigh train and bus stations with ample parking and wheelchair access

One exciting aspect of the new clinic is the potential it offers in the area of clinical teaching. So often in feedback students comment that they would like more experience with people with a developmental disability in a real clinical setting. Now we can offer this opportunity to students, practitioners and allied health workers. Consultations in the main clinical room can be observed from the adjacent room by means of a one-way mirror and a microphone.

From left to right: Professor James Angus, Dean of Medicine, University of Melbourne, Associate Professor Bob Davis, Director, CDDHV, the Hon Sheryl Garbutt, Minister for Community Services and Professor Edward Byrne, Dean of Medicine, Monash University at the launch of the centre's new clinical facility at Oakleigh, December 2004.

By prior arrangement, small groups of observers, with or without a tutor, will be able to access this facility and discuss their observations. This complements other activities – all aimed at ensuring that medical students and practitioners are better trained, better informed and better supported in their care of people with developmental and intellectual disabilities throughout the State.

The redevelopment of the clinic and office facilities at Oakleigh has also opened up exciting research opportunities. These opportunities will build on our previous and current projects, which have focused on the health and well being of adults with developmental disabilities.

Adults with developmental disabilities also have a much greater incidence of mental health problems than people in the general community. This high incidence is reflected in our research data collection and account for a large percentage of referrals to CDDHV clinics.

Another area of need is that of human relations and sexuality education and counselling.

Understanding an individual's overall sexual knowledge is an important component in the planning of both education and treatment, particularly in regard to the social, legal and ethical implications of socio-sexual behaviour. The Assessment of Sexual Knowledge (ASK) was developed for this group, and is the result of collaboration between the CDDHV and the Department of Human Services. The tool was recently evaluated for validity and reliability and the results published in the *Journal of Intellectual and Developmental Disability*.

Further information about the centre can be found on our website www.cddh.monash.org.au. Look on our website over the coming months for progress reports on:

- Early identification of symptoms and monitoring of progress of Alzheimer's disease in adults with down syndrome
- Case studies of human relations educational counselling
- Multiple determinants of challenging behaviours
- Assessment of depression of adults with intellectual disability
- Longitudinal survey of the health and wellbeing of adults with developmental disability.



Developing Better Health Outcomes for People with Developmental Disability”

The combined International Roundtable of the Health Issues and Mental Health Special Interest Research Groups (SIRG) of the International Association for the Scientific Study of Intellectual Disability (IASSID) and the Annual Conference of the Australian Association of Developmental Disability Medicine (AADDM).

28 to 30 September 2005
Carlton Crest Hotel, Melbourne



Themes for the day

Day one – Wednesday 28 September 2005

Physical Health

Day two – Thursday 29 September 2005

Health Care Service Infrastructure – State, National and International Perspectives

Day three – Friday 30 September 2005

Behaviour and Psychiatric Health

Welcome addresses

Associate Professor Robert W Davis

Director, Centre for Developmental Disability Health Victoria

This year's conference has combined the Annual Roundtables of the Health Issues and Mental Health Special Interest Research Groups of IASSID and the Annual Conference of the Australian Association of Developmental Disability Medicine. The theme for this conference has been 'Developing Better Health Outcomes for People with Intellectual Disability'. To achieve these outcomes not only do we need to have a knowledge of how to do this as individual health practitioners but on also knowledge on the type of infra-structure and support systems that are needed.

Health is not simply something one acquires by attending a medical practitioner but is dependent on our genetic susceptibilities and a myriad of day-to-day decisions by ourselves, our family and carers and our community.

I aimed to have this conference represent the broader vision of health and health delivery and for its registrants to have an insight into how other professionals, services, states and countries tackle health issues and how they may adapt these experiences to their own circumstances. I would like particularly to thank our staff at the Centre for Developmental Disability Health Victoria (CDDHV) particularly Faye Alphonso and Caroline Menara for their help in organising the conference and putting together this program. There will be opportunities for the acquisition of knowledge and skills, discussion and debate but most of all to share our vision at the CDDHV of better health and better lives for people with developmental disabilities.



Professor Leon Piterman

Head, School of Primary Health Care, Faculty of Medicine, Nursing and Health Sciences, Monash University

As head of the School of Primary Health Care at Monash, within which the Centre for Developmental Disability Health Victoria (CDDHV) resides, I would like to welcome you to the conference.

The CDDHV was established in 1998 within the Department of General Practice as a joint initiative between Monash University and the University of Melbourne and funded by the Department of Human Services in recognition that with increasing community based care there was a need to develop expertise amongst medical students, general practitioners and the primary health care system on the health issues facing people with developmental disabilities. The broad range of health problems that present in this population mean that their health issues are not adequately covered by any existing specialty group and it is critical for optimal health care management that general practitioners as gate keepers for access to services and case managers for complex health problems are knowledgeable and competent in

the management of people with developmental disabilities. The complex health problems seen in this group often require a multi-disciplinary approach. The School of Primary Health Care at Monash University is now in the unique position of having departments of general practice, social work, physiotherapy, occupational therapy and ambulance studies in the same school providing opportunities to share educational resources, develop clinical services and carry out collaborative inter-disciplinary research. People with developmental disability use all these services and there is often a need for better coordinated inter-disciplinary care so the CDDHV is in a key position to continue its role of building better access to services for this group.

I am pleased to see that this conference brings together people from the broader health care community and hope that you find it inspires you to build your networks and enhance your continued interest in the field.



A word from

The Hon Sheryl Garbutt, Minister for Community Services, State Government of Victoria

On behalf of the Victorian Government I would like to welcome the delegates to this conference. It will be an important opportunity to share ideas and expertise about one of our really critical issues – the health needs of people with intellectual disability – and I commend you for your interest in, and commitment to, an issue that many others have found too difficult to address.

Victoria has led the way in Australia with the establishment of the developmental disability units at Monash University and the University of Melbourne in 1991 and the Centre for Developmental Disability Health Victoria in 1998. Over the next 2 years we will be continuing to build a 'Fairer Victoria' for everyone, by identifying and dealing with inequality. While we are challenged by the increasing need for our services, as the population ages and people's needs become more complex, we also want to build a service system that responds more quickly, and in more flexible ways, to what people are telling us they want.

To do this we are addressing the disadvantage faced by people with disabilities by making sure

that universal services are more accessible and relevant. Health services are clearly a vital part of that picture.

If we are to build services that meet communities' current and future health needs we have to make sure those services are accessible to everyone, and that they are connected to diverse and inclusive communities. That means building stronger communities, healthier communities, communities where everyone has a place and a part to play.

The issues we face in Victoria no doubt are much the same as those faced in communities within Australia and around the world. If we are to effectively deal with health issues then we need to develop a better understanding of the physical and mental health issues faced by people with developmental disability and develop better strategies in dealing with them.

By the sharing of knowledge at this conference we help each other work towards better health for people with developmental disabilities.



Picture taken at the launch of the new CDDHV clinical facility at Oakleigh, December 2004

Mr Arthur Rogers, Disability Services, Executive Director, Department of Human Services, State Government of Victoria

I would like to warmly welcome delegates to this important conference. As you may already be aware this conference is being held in a State which has a very strong policy platform which supports our attempts to improve health outcomes for people with a disability.

Victoria's State Disability Plan sets new and exciting directions for Disability Services. These directions speak to our vision of a more inclusive community, where people with a disability have the same rights, opportunities and responsibilities as all citizens of Victoria.

It provides a framework for promoting inclusion and participation for people with a disability across all areas of life-including disability supports, health and community services, recreation, education, employment, transport and housing.

A major challenge for us in achieving the vision of the State Plan is to improve health outcomes for people with a disability. I look forward to participating in the conference, and learning from the experience which will be shared in the time we spend together.



Messages from

Professor Edward Byrne

Dean, Medicine, Nursing and Health Sciences, Monash University

I would like to firstly welcome the delegates to the conference on behalf of the Faculty of Medicine, Nursing and Health Sciences at Monash.

The medical faculty at Monash University is committed to providing excellence in education and research. The faculty prides itself on providing a medical and health sciences education that prepares students for the challenges they will face in professional life, both by virtue of the knowledge base they acquire, impartment of the skills needed to constantly update that knowledge base in a changing world, and reinforcement of the human skills and ethical base necessary to practice as outstanding health professionals.

In years gone by students have had little contact with people with developmental disability. Monash has been recognised by independent research as including more teaching on developmental disability than any other medical school in Australia. Staff at the

Centre for Developmental Disability Health Victoria have made a significant contribution to the undergraduate teaching program where the health issues of people with intellectual disability have been integrated into the curriculum. The recent development of clinic rooms at the centre will facilitate hands-on teaching opportunities for final-year students and registrars through contact with the clinicians working at the centre.

The centre continues to develop its research capacity on physical and mental health issues of people with developmental disabilities majoring in the health issues of challenging behaviour, ageing and mental health. This conference itself is an acknowledgement of the important role that the Centre for Developmental Disability Health Victoria has in health both nationally and internationally. I hope that you enjoy the conference and your stay in Melbourne.



Professor Jane Gunn

Acting Head, Department of General Practice, University of Melbourne

On behalf of the Department of General Practice at the University of Melbourne I would like to welcome the participants of the conference to the Melbourne.

Our Department of General Practice aims to build effective links between general practice and the wider health care system. In keeping with this, between 1992 and 1997 one of the two Developmental Disability Units in Melbourne was attached to our Department of General Practice. These units were the first of their kind in Australia and the fore runners of the CDDHV. Nick Lennox the previous head of the Developmental Disability Unit in Melbourne has since moved to take on a key position in the field as head of the Queensland Centre for Intellectual and Developmental Disability.

The Centre for Developmental Disability Health Victoria (CDDHV) which evolved from these units is joint initiative of the University of Melbourne and Monash University. The CDDHV continues to provide valued input into the

curriculum development and the undergraduate teaching program in developmental disability in the undergraduate curriculum at Melbourne. Our current Director of Education Assoc. Professor Steve Trumble, a past head of the Monash Developmental Disability Unit at Monash, is a Member of the CDDHV's executive committee. The Department of General Practice is proud of its contribution to development of the field of developmental disability medicine and supports the CDDHV which has similar goals to its own in particular to serve the community by contributing to health policy development, health care delivery, health research and addressing inequalities in health care delivery. As these are the very issues that will be addressed at your conference we wish you every success during your visit to Melbourne.

The Helen Beange Oration

Professor Mike Kerr will present the 2005 Helen Beange Oration

It is very fitting that we follow up the informal oration given last year in Queensland with the first official 'Helen Beange Oration' at this joint conference of the IASSID Health SIRG and the Australian Association of Developmental Disability Medicine. Helen has played a key role in the development of both these organisations. Helen's article *Medical Disorders of Adults with Mental retardation: a population study* published in 1995 at a time in her life when many would be retiring has been one of the central pieces of research behind the recognition of the health problems of people with intellectual disability. Helen's dedication to this population has served as an inspiration to many of us in the field of developmental disability medicine.



About the Keynote Speakers

Professor Mike Kerr

Learning Disability Psychiatry,
Department of Psychological Medicine, Cardiff University, UK

Michael Patrick Kerr is Professor of Learning Disability Psychiatry, in the Department of Psychological Medicine, Cardiff University in the UK. This post combines a research portfolio with an active epilepsy service providing 2 epilepsy clinics per week and a further 16 peripheral epilepsy clinics per year.

Mike is also involved in providing input into the Cardiff Rett Clinic held twice yearly. In addition, Mike holds an honorary post as consultant neuropsychiatrist to the Neuropsychiatric service at Whitchurch Hospital Cardiff. Mike's research interests are in the health of people with learning disabilities, epilepsy and the

quality of primary medical care. Amongst many other professional recognition positions, he currently also holds the position of Chair of the Health Issues Special Interest Research Group of IASSID. Mike will present the 'Helen Beange Oration' on: 'The evidence base for health outcomes in people with intellectual disability'



About the Keynote Speakers

Associate Professor Dinah Reddihough



Dinah Reddihough is Director of Child Development and Rehabilitation at the Royal Children's Hospital, Melbourne and a leader of the Australasian Academy of cerebral palsy and Developmental Medicine. She is involved in the clinical care of children with disabilities, particularly those with cerebral palsy. Her research program is focused on gaining an improved understanding of the causes and outcomes of disabilities in childhood and has published extensively on cerebral palsy.

Dr Adam Scheinberg



Dr Adam Scheinberg is a Paediatric Rehabilitation Specialist who is Head of the Physical Disability Service at The Children's Hospital at Westmead in Sydney, New South Wales. The Physical Disability Service sees over 2800 children each year with physical disability, primarily cerebral palsy and spinal cord injury. There is a multidisciplinary assessment clinic as well as treatment programs including Botulinum toxin-A, Intrathecal Baclofen infusion, Selective Dorsal, Rhizotomy and Rehab-Orthopaedic clinic. His research interests are in the effectiveness of the above treatments, efficacy of therapy following spasticity interventions and team functioning within the health care system.

Mr Paulo Selber MD

Paulo Selber is an orthopaedic surgeon at the Royal Children's Hospital in Melbourne and has played a key role in developing techniques at the RCH in the orthopaedic management of cerebral palsy. Paulo is originally from Brazil and previously worked at AACD – Sao Paulo – Brazil where he was a consultant orthopaedic surgeon involved in planning, coordinating and starting the Gait Lab from 1996 until 2000. He moved to Australia in 2001 to take up a Fellowship in Paediatric Orthopaedic Trauma. His main interests lie in the treatment of children with neuromuscular diseases such as cerebral palsy, myelomeningocele and muscle dystrophy. He is part of the gait lab team in the reporting process and in the treatment of these children.

Mr Arthur Rogers



Arthur Rogers is the Executive Director Disability Services, Department of Human Services, State Government of Victoria. He has experience in the Department as the Regional Director of the Eastern Metropolitan Region and the Barwon/South Western Region. Prior to joining the, then Health Department in 1991 Arthur worked as a Chief Executive Officer of State and Commonwealth funded community health and community aged care agencies.

Mr Murray Couch



Murray Couch is a sociologist, a Research Fellow at CDDHV and a Senior Research Fellow at the Australian Research Centre in Sex, Health and Society (LaTrobe University). He is interested in the deployment of mixed social research methodologies to produce knowledge that informs public policy and provides evidence for project and program design and evaluation.

Professor Robert A Cummins



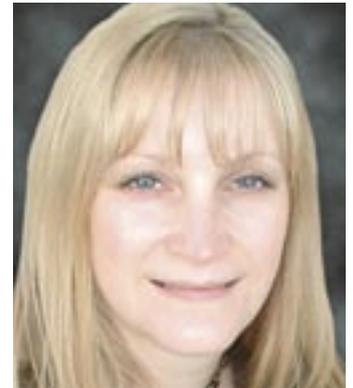
Professor Robert A Cummins holds post-graduate degrees in physiology and psychology from the University of Queensland and the University of Western Australia. He was appointed to a Personal Chair in Psychology at Deakin University in 1997. He is a Fellow of the International Society for Quality-of-Life Studies and the Australian Psychological Society. His current research program is directed towards theory development concerning the quality of life construct, and how such understanding can be used to improve the life experience of people who are medically or socially disadvantaged.

Senator Lynn Alison Senator for Victoria



Senator Allison is the Leader of the Australian Democrats. She is the party's national spokesperson on Education and Training, Energy and Resources, Health and Ageing, Treasury and Prime Minister and Cabinet. She was elected to the Federal Parliament in 1996 and re-elected in 2001. From 2002 to 2004 she served as Deputy Leader and Party Whip. Senator Allison has been an active Senate participant and outspoken campaigner on health, education, environment and nuclear issues. She has chaired the powerful Senate, Environment, Communications, Information Technology and the Arts References Committee, which conducted 10 key environment inquiries and made hundreds of recommendations. She also initiated three inquiries into uranium mining and is currently chairing the Democrats-initiated National Mental Health inquiry.

Professor Sally-Ann Cooper



Professor Sally-Anne Cooper was appointed to the University of Glasgow in 1999 to its foundation Chair of Learning Disabilities, and since then has established the Glasgow University Affiliated Program in Learning Disabilities. Sally-Ann also works as an Honorary Consultant in Intellectual Disabilities Psychiatry within NHS Greater Glasgow. She previously worked in the Midlands of England, having originally qualified from the University of London. Her research interests are in health improvement for adults with intellectual disabilities, particularly mental health. Sally-Ann has published extensively in this area. She chaired the working group to establish diagnostic criteria for psychiatric disorders for use with adults with intellectual disabilities (DC-LD) on behalf of the Royal College of Psychiatrists (published by Gaskell Press in 2001); and on behalf of NHS Health Scotland, chaired the Scottish intellectual disabilities health needs assessment, published in 2004.

About the Keynote Speakers

Professor Tony Holland

Tony Holland studied medicine at University College, London qualifying in 1973. After some years in general medicine he trained in psychiatry at the Institute of Psychiatry and the Maudsley Hospital, London. He subsequently specialised in the field of learning disabilities and held a senior academic post at the Institute of Psychiatry until moving to the University of Cambridge in 1992. In 2002 he was appointed to the Health Foundation Chair in Learning Disabilities awarded to the University. He works as a psychiatrist in the local service for adults with learning disabilities. His research interests include investigating the relationship between particular syndromes and psychiatric and behavioural disorders and clinical/legal issues. He has been an adviser to the UK Government on the recent mental capacity legislation. Since 2004 he has been editor of the *Journal of Intellectual Disability Research*.

Professor Phil Davidson



Philip W Davidson is Professor of Paediatrics and Chief of the Strong Center for Developmental Disabilities at the University of Rochester's Golisano Children's Hospital. His main research interests are the environmental effects on foetal development, and health outcomes among older adults with intellectual disability. He is past president of Division 33(MR/DD) of the American Psychological Association, and of the Psychology Division of the American Association on Mental Retardation. Currently he co-chairs the Special Interest Research Group in Aging and is a member of Council for IASSID.

The Program

Day one Physical Health

9.15–9.30 am	Official Opening The Hon Sheryl Garbutt Minister for Community Services, Government of Victoria
9.30–10.30 am	First Keynote Address The 'Helen Beange Oration' The evidence base on health outcomes in people with intellectual disability. Professor Mike Kerr, Cardiff University, UK
10.30 –11.00 am	Morning Tea

11 am – 12.30 pm Parallel sessions one		
Breakout Room 1, State Room	Breakout Room 2, Belair Room	Breakout Room 3, Washington 1 and 2
Physical Health	Health Management	Nutrition / Cerebral Palsy
Gastrointestinal conditions in adults with down syndrome. Robyn Wallace	Developments in the management of epilepsy in people with intellectual disability. Mike Kerr	Statewide nutrition surveillance program for people with a disability. Sue Milner
Factors affecting the prevalence of vitamin D deficiency in people with intellectual disability, comparison of treatment regimes and effect of these on fractures. Michael Nugent and Simon Vanlint	Occupational therapy and physiotherapy services in government primary schools. Jenny Snelling	A ten-year experience with PEG nutrition in adolescents with multiple disabilities. Lynette Lee
Vitamin D status of people with developmental disability. Jane Law and Seeta Durvasula	A program to facilitate health and well-being in a group of young adult persons with spina bifida by providing a customised gym program accessing community facilities. Christine Blackburn	Nutritional rehabilitation of children with cerebral palsy. Fiona Arrowsmith

12.30–1.30 pm	Lunch
1.30–2.30 pm	Second Keynote Address Newer treatments for cerebral palsy. Associate Professor Dinah Reddihough, Dr Adam Sheinberg and Mr Paulo Selber (Royal Children's Hospital Melbourne and the Children's Hospital at Westmead)

2.30–3 pm Parallel sessions two		
Breakout Room 1, State Room	Breakout Room 2, Belair Room	Breakout Room 3, Washington 1 and 2
Physical Health	Epilepsy	Nutrition / Cerebral Palsy
The risk factors for coronary artery disease among older adults with intellectual disability. Robyn Wallace	Community use of intranasal midazolam for managing prolonged seizures. Margaret Kyrkou	Nutritional management in people with developmental disability: the influence of caregivers. Jodie Bennett and Seeta Durvasula

3–3.30 pm	Afternoon tea
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3.30–5 pm Parallel sessions three		
Breakout Room 1, State Room	Breakout Room 2, Belair Room	Breakout Room 3, Washington 1 and 2
Health Systems	Human Relations	Dental-Intellectual Disability Interface
Epilepsy and disability in East Timor – developing a system of sustainable service delivery. Helen Somerville	Working on the margins. Mark Stevenson	Dental care for people with developmental disabilities. Warren Shnider
Opportunities for community based physical activity for young people with a disability – an overview of international practice and trends. Kelli Nicola-Richmond	Human Relations Workshop 4 pm	Dental basics for swallowing and nutrition. Kerrie Punshon
Neuro developmental outcomes of the Seychelles Child Development Study. Philip Davidson	Sexuality and disability workshop. Jenny Butler and Jenny Galea	Thegosis: tooth sharpening. John Chrystie

5.30–6.30 pm	Annual General Meeting of the Australian Association of Developmental Disability Medicine (AADDM)
6.30–8 pm	Welcome Cocktail Party and launch of CDDHV multimedia educational resource

Day two

Health Care Service Infrastructure: State, National and International Perspectives

7.30–8.45 am

Breakfast Meeting – Washington Rooms 1 and 2

Workshop sponsored by the Apex Foundation for research into Intellectual Disability hosted by Associate Professor Michael McKay, Head of School of Psychology, Australian Catholic University and Associate Professor Dinah Reddihough AO of the Royal Children's Hospital Melbourne.

The purpose of the breakfast is to establish research priorities for people with developmental disabilities. (see flyer in satchel – register your interest early as numbers are limited).

9–9.30 am

First Keynote Address

[Health issues and the policy and practices of disability services.](#)

Mr Arthur Rogers, Executive Director, Disability Services
Department of Human Services, State Government of Victoria

9.30–11 am

International Forum on:

[The development of physical and psychiatric health services for people with intellectual disability internationally: What can we learn from each other?](#)

Facilitated by Murray Couch, Research Fellow, CDDHV

The Panel

United Kingdom:	Professor Tony Holland	United States:	Associate Professor David O'Hara
Scotland:	Professor Sally Ann Cooper	Canada:	Dr Thomas Cheetham
New Zealand:	Dr Mhairi Duff	Australia:	Associate Professor Nick Lennox
Netherlands:	Associate Professor Bob Davis (presenting for Mariylei Meijer and Dr Henry Lantman)		

11–11.30 am

Morning Tea

11.30 am – 12.30 pm – Parallel sessions one			
Breakout Room 1 State Room	Breakout Room 2 Belair Room	Breakout Room 3 Washington 1 and 2	Breakout Room 4 Washington 3 and 4
Health Care Delivery	Carer Health Care Skills	Educating Undergraduates	From Rights to Reality
Canadian health care and the health of Canadians with intellectual disabilities. Helene Ouelette-Kuntz, Tom Cheetham and Deborah Elliott	Working together for better health outcomes. Nicola Chirlan and Narelle Marshall	Healthcare scenarios in developmental disability medicine. Jane Tracy	The right to a healthy life – a perspective from an intellectual disability advocacy organisation. Helena O'Connell
Coordinating to improve health outcomes in people with intellectual disability. Ron Hyder	Direct care staff's perspectives on meeting the health needs of people with intellectual disability. Margaret Nicol	Fitting disability education to meet diverse needs of developing countries. Judi Moyle and Teresa Iacono	Health assessments: where to from here? Nicholas Lennox

12.30–1.15 pm

Lunch

Posters in the foyer

A health promoting approach to osteoporosis prevention for people with a disability. Sue Milner

ASK – A sexual knowledge assessmentn tool for people with an intellectual disability.

PHR – Personal Health Records.

A CD depicting healthcare scenarios in developmental disability medicine.

1.15–2 pm

Second Keynote Address

[The relationship between quality of life and health outcomes for people with intellectual disability.](#)

Professor Bob Cummins, Deakin University

2–3.30 pm – Parallel sessions two

Breakout Room 1 State Room	Breakout Room 2 Belair Room	Breakout Room 3 Washington 1 and 2	Breakout Room 4 Washington 3 and 4
Advocacy and Health Professionals	Health Care Delivery Systems	Physical Health and Quality of Life	Targeting Intellectual Disability Populations
Genetic Health Services Victoria and Genetic Support Network Victoria – partners in improving services for families with genetic conditions. Susan Fawcett and Agnes Bankier	Measuring the effectiveness and outcomes of Victorian school programs for students with a disability. Susan Vilé	What About Me. Penny Kendall and Denise West	Lost in transition – issues of transition to adult health care for young people with developmental disabilities. Felicity Sloman
A specialist medical practice in developmental disability in Australia – the rehabilitation medicine perspective. Lynette Lee	Access Assistant Program: providing invasive health care in educational settings. Sharon Huckel	Gastrostomies – improving quality of life? Lyn Tatt and Hilary Johnson	Evaluation of family-centred care for young children with intellectual disability in Western Australia. Amanda Wilkins
When adults with intellectual disability need to go to hospital: improving the experience and outcomes. Robyn Wallace	A comparison of Australian and UK Psychiatry training and services to meet the mental health needs of adults with intellectual disability. Jenny Torr	Feeding relating quality of life in children with quadriplegic cerebral palsy: health professionals perceptions. Angie Morrow	Early outcomes from a population-based intellectual disability database in Western Australia. Helen Leonard
The metabolic social worker goes into bat – a case study in advocacy. Flora Pearce		Feeding relating quality of life in children with quadriplegic cerebral palsy: parental perceptions. Angie Morrow	

3.30–4 pm Afternoon tea

4–5.30 pm – Parallel sessions three

Breakout Room 1 State Room	Breakout Room 2 Belair Room	Breakout Room 3 Washington 1 and 2	Breakout Room 4 Washington 3 and 4
A Systems Perspective on Health Services	Innovations in Health Education	Improving Access to Health Services	Health and Quality of Life
Individual planning for healthier outcomes in the community. Sue Jamieson, Mirella Danelutti and Mark Grant	Does the written information make sense? Achieving better health outcomes by developing accessible written information. Katie Lyon for Cathy Basterfield	Improving access to National Health Service Walk-in Centres for people with learning disabilities. Matthew Godsell	A quality of life scale for children with cerebral palsy: QOL from the perspective of families. Elise Davis
Meeting the medical needs of adults with developmental disabilities in an inclusive system. Philip Graves	A website about diabetes for adults with intellectual disability – development and evaluation. Therese Rey-Conde	Why are some adults with an intellectual disability more difficult to provide services to? Chad Bennett	Promoting health of families with children with disabilities: A health mentoring project. Linda Goddard and Sandra Mackey
What to do about health disparities among persons with intellectual disability: some US strategies combining a public health and clinical approach. David O'Hara	Better Health Channel Articles: information made easy. Katie Lyon	Living with a disability. John Entwhistle	The role of direct support workers in health care for adults with intellectual disabilities. Alex Phillips

5.30–6.30 pm Annual General Meeting – Health SIRG IASSID

7–11 pm Conference dinner at River Room, Crown Towers Hotel, Southbank, Melbourne

Day three

Behaviour and Psychiatric Health

9–9.30 am	First Keynote Addresses Progress report on the findings of the Senate Standing Committee on Mental Health. Senator Lyn Allison, Leader of the Australian Democratic Party
9.30–10.30 am	The evidence base for mental health outcomes for people with developmental disability. Professor Sally-Ann Cooper, University of Glasgow
10.30–10.45 am	Morning Tea
10.45–11.15 am	The clinical implications of our knowledge of behavioural phenotypes. Professor Tony Holland, University of Cambridge

11.45 am – 12.45 pm Parallel sessions one		
Breakout Room 1, State Room	Breakout Room 2, Belair Room	Breakout Room 3, Washington 1 and 2
Behaviour Phenotypes	Management Psychiatric Disorders and Autism	Challenging Behaviours
Rett syndrome research in Australia and internationally – past, present and future. Helen Leonard	Experience of a randomised control trial of risperidone and haloperidol in adults with intellectual disability. David Harley	Profiles of adults with intellectual disability and behaviour problems. Teresa Iacono
Update on Fragile X Syndrome (FXS). Jonathan Cohen	Should form follow function? What role do psychiatrists have in the care of offenders with intellectual disabilities? Mhairi Duff	Gaining perspective in the causality of self-injurious behaviour (SIB) in people with intellectual disability. Robert Davis
Life threatening physical health problems masquerading as behavioural/mental health disorders: two case studies. Helen Somerville	The effectiveness of a parent education and skills program of rural parents with a pre-school child with autism. Avril Brereton	When nothing you do seems to work: assisting to turn around worker's perceptions of challenging behaviour in intellectual disability clients. Malini Singh and John Lord

12.45–1.30 pm	Lunch Retts Video Screened in State Room over Lunch interval
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1.30 – 2.15pm	Second Keynote Address Intellectual disability, ageing and health outcomes: mind the gap. Professor Phil Davidson, University of Rochester, New York
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2.15–3.45 pm Parallel sessions two		
Breakout Room 1, State Room	Breakout Room 2, Belair Room	Breakout Room 3, Washington 1 and 2
Anxiety Disorders	Dual Disabilities Doubled	Autism
The burden and cause of anxiety disorders in individuals with intellectual disability. Bruce Tonge	Improving addictions services for clients with developmental disability. Graham Dyson	Screening for autism in young children with developmental delay. Kylie Gray
Assessing anxiety in adults with intellectual disability. Stephen Edwards	A life worth living – borderline personality disorder and intellectual disability: dialectic behaviour therapy. Marleen Verhoeven	Stress, sleep and mental health problems in people with autism spectrum disorder. David Hamilton
Interventions for anxiety in adults with intellectual disability. Stephen Edwards	Personality disorder in intellectual disability: characteristics and health outcomes. J Tomasoni and Andrew Pridding	The difficulties in differentiating autism from Schizophrenia in adults with intellectual disability. Chad Bennett

3.45–4.15 pm	Afternoon Tea
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4.15–5 pm Parallel sessions three		
Breakout Room 1, State Room	Breakout Room 2, Belair Room	Breakout Room 3, Washington 1 and 2
Aged Care Workshop	Communication Workshop	Diagnostic Criteria – Learning Disability (DC-LD)
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Part 2: Clinical assessments of Alzheimer's disease in people with down syndrome and treatment with cholinesterase inhibitors. Jenny Torr		

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Day one: First Keynote Address

The evidence base on health outcomes in people with intellectual disability.

Professor Mike Kerr

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There exists a considerable body of evidence that highlights deficits in the health of people with an intellectual disability. This published evidence is supported by the common experience of people with an intellectual disability of dissatisfaction with the health care they receive.

The challenge for our research community is in defining these deficits in health in such a way as to provide a clear message of what the problem is, why it occurs, to quantify it and most importantly to provide solutions. All this needs to be done in a manner that recognises the delicate balance of providing care in such a way as not to further stigmatise people with an intellectual disability. This paper will explore health outcomes through these key domains: (i) defining health outcome that is most relevant to this population, (ii) quantifying health outcomes and (iii) using health outcomes to drive interventional research.

Health outcomes should reflect those common to the population as a whole but recognise where a special focus is needed due to specific issues facing this population. Thus a model of inequality/disparity in health best identifies the deficits in health faced by this population. In particular such an approach allows us to recognise the broad determinants of ill health thus allowing health outcomes to include important social challenges faced by people with an intellectual disability, such as access to employment. The measurement of health outcome combines generic population measures, such as life expectancy, with specific measures validated in this group.

It is of course not sufficient to simply recognise deficits we must explore solutions so interventional research is needed to make the real changes for this population.

Day one: Session one – Physical Health

Gastrointestinal conditions in adults with down syndrome.

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Adults with down syndrome (DS) are prone to a number of gastrointestinal conditions by nature of the syndrome (eg celiac disease), as well as other conditions related to environmental conditions or functional impairment (eg *Helicobacter pylori* infection). A vigilant approach to these conditions is important for the clinician as missed pathology may have significant adverse consequences for patients.

A literature review of such conditions occurring in adults with DS including coeliac disease, *H.pylori*, reflux, constipation, hepatitis, inflammatory bowel disease will be presented in the light of prevalence, symptoms, link to syndrome, diagnosis and treatment. In addition, the results of an audit on the gastrointestinal conditions among adults with DS attending a specialised clinic in Brisbane will be presented and reviewed. Examples of clinical difficulties in the practical diagnosis and management of these conditions will be raised for discussion.

Factors affecting the prevalence of vitamin D deficiency in people with intellectual disability, comparison of treatment regimes and effect of these on fractures.

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Vitamin D is an important substance in maintaining the strength and resilience of bone and muscle. People with an intellectual disability (ID) have been shown to have a greater prevalence of vitamin D deficiency than those in the general population. This contributes to an increased rate of falls and fractures, and a subsequent increase in morbidity and mortality in these people.

Factors such as diet, immobility, decreased exposure to sunlight and use of medications, including anticonvulsants have been shown to lead to low levels of vitamin D. This study includes 345 people with ID living in institutional settings and community homes. It looks at vitamin D levels in this population, as well as factors such as age, sex, nutritional status, mobility, bone density and medications which may influence levels.

Replacement with ergocalciferol, currently the only commercial form of vitamin D available in this country, and cholecalciferol are compared. Fracture incidence for up to five years before and after intervention will be examined.

Preliminary results confirm a much greater prevalence of vitamin D deficiency (over 65 per cent), and a greater incidence of fractures compared to people without intellectual disability.

It is our intention to create an instrument which uses the above factors to predict who should be given vitamin D replenishment regardless of laboratory values, which are not always practically obtainable. With vitamin D receptors located widely in other body organs and tissues broader discussion will touch upon other possible benefits of replacement.

Vitamin D status of people with developmental disability.

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Vitamin D deficiency is well recognised in many segments of the population, particularly the elderly or those who are institutionalised. However, the prevalence of vitamin D deficiency in people with developmental disability has not been as well studied. Many of the studies have examined the vitamin D status of children or adults in institutional care or in those with severe intellectual disability and on anticonvulsant therapy. Centre et al.¹ found a high prevalence of low vitamin D levels in a population based sample in northern Sydney, but there was no association with anticonvulsant therapy. The purpose of this study is to determine the vitamin D status and associated factors in people with developmental disability attending a specialised medical clinic.

The NSW Developmental Disability Health Unit is a specialised medical clinic for adolescents and adults with developmental disability. The majority of those seen live in the community, and come from metropolitan Sydney and beyond, including regional and rural areas. They present for a general medical evaluation, assessment of difficult behaviours or for specific health problems. The majority of people have their vitamin D level measured as part of their evaluation.

In this study, serum Vitamin D levels, related biochemical indices, demographic factors, potential risk factors (eg. anticonvulsant therapy, malabsorption), and consequential conditions such as osteoporosis will be determined. Regression analyses will be used to determine significant risk factors for and consequences of vitamin D deficiency. The results and their implications for clinical practice and future research will be discussed.

1. Centre J, Beange H & McElduff A.(1998) People with mental retardation have an increased prevalence of osteoporosis: a population study. *American Journal on Mental Retardation* 103 (1):19-28

Day one: Session one – Health Management

Developments in the management of epilepsy in people with intellectual disability.

Professor Mike Kerr

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Epilepsy remains arguably the most serious common co morbidity experienced by people with an intellectual disability. As such it holds something of a special place for those involved in the treatment and care of this group.

In general developments in management should mirror those for people with epilepsy as a whole. That is, advances in therapeutics, a greater understanding of the causes and outcome of the epilepsies and improvements in the delivery of care.

This presentation will firstly address these issues and how they relate to the care of people with an intellectual disability who have epilepsy particularly focussing on novel therapies and the increase in clinical guidelines for the management of epilepsy.

Secondly I will assess recent developments that are specific to areas of particular importance in people with an intellectual disability. These include therapeutic trials in this population and developments in understanding the impact of management changes.

Occupational therapy and physiotherapy services in government primary schools.

Ms Jenny Snelling

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This three-year project was initiated by the RCH Education Institute in 2002 to develop best practice guidelines for the delivery of occupational therapy and physiotherapy services in government primary schools. It is guided and supported by a reference group consisting of members from:

- Association for Children with a Disability
- Australian Association of Occupational Therapy – Victoria
- Australian Physiotherapy Association – Victorian Branch
- Department of Education and Training
- Principals' Association of Special Schools
- Royal Children's Hospital
- Scope, Victoria

The project has had three stages:

- Literature review on international best practice in service delivery.
- Collection and analysis of local issues via a commentary group comprising of health and education professionals and parents and a statewide Delphi survey of schools.
- Action-based research involving five Victorian government primary schools.

Now in its final year, the project is utilizing its research findings to develop a guide for schools and therapists that illustrates and promotes exemplary cross-disciplinary collaborative practice and understanding in service delivery.

This presentation will examine the key findings from each stage of the project and explain how the gathered data has been used in the development of a statewide guide for schools and therapists.

A program to facilitate health and well-being in a group of young adult persons with spina bifida by providing a customised gym program accessing community facilities.

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Stephanie Taylor – Spina Bifida Foundation of Victoria

Kelli Nicola-Richmond – SCOPE Vic

Scott Taylor – Heartwell Fitness

Dr Elizabeth Lewis – Monash Medical Centre, Spina Bifida Clinic

Melanie Toy-Laing – Monash Medical Centre

Purpose: Despite improvement in medical interventions, clinical experience suggests that young adults with spina bifida are not typically developing into active citizens, enjoying further education and employment, or developing an enduring social life and intimate partnerships. This is due to a complex range of physical health issues, combined with the societal impact of a physical disability which creates a lack of social confidence and self esteem. (Dow R, 2004). The purpose of this study was to evaluate the health and well being outcomes of a facilitated community gym program.

Method: A clinical intervention study was undertaken using a Quality of Life questionnaire (SF-36), goal oriented questionnaire (COPM) and a measurement of fitness (6 Min walk/push test), both pre and post intervention to evaluate the efficacy of a community based exercise program. Sixteen clients with spina bifida participated in a twice weekly gym program, personalised to their individual needs and completed over 3 months.

Results: Results showed a significant improvement in all areas that were assessed, particularly relating to self confidence and motivation to exercise. Participants demonstrated a desire to retain and improve their fitness levels by accessing community facilities. The main issue for most participants was the personal cost of utilising public facilities on a limited income.

Conclusion: In a society where health costs are escalating assisting people with spina bifida to maintain their health and wellbeing can be justified in order to defray longer term costs of care for these individuals. If this can be achieved through inclusive community programs it should be encouraged at all levels of disability planning.

Day one: Session one – Nutrition / Cerebral Palsy

Statewide nutrition surveillance program for people with a disability.

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The Victorian Department of Human Services in collaboration with Deakin University is establishing a nutrition surveillance program to identify individuals who are at nutritional risk and to create an ongoing monitoring database to inform policy direction, workforce development, health promotion strategies and research. A modified version of a nutrition and swallowing screening checklist developed by NSW State Government¹ forms the basis of data collection for this program.

Initial results indicate that this process is highly effective in identifying people at risk of nutrition and swallowing problems that had not been diagnosed through contact with GP's and other health professionals. Some of the key risk identifiers were underweight, requirement for assistance with eating, constipation, dental problems, recurrent chest infections, and coughing, gagging or choking whilst eating or drinking. All individuals were subsequently diagnosed with nutrition and/or dysphagia related conditions requiring professional intervention. Analysis of the collated data has also identified the need for revision of training for direct support workers in key health management areas, revision of operational policy and guidelines, targeted research and the building of capacity of the health sector to diagnose and manage some health areas for this population sub group. This program has also increased the confidence and skill of direct support workers to identify when a person is at risk of declining health and making linkages to appropriate health professionals. Expansion of this program to a broader health surveillance program is considered feasible and currently under investigation.

References

1. NSW Department of Ageing, Disability and Home Care. Nutrition in Practice Manual. 2000.

A ten-year experience with PEG nutrition in adolescents with multiple disabilities.

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Since 1993 the New South Wales (Australia) Ombudsman has been reviewing the quality of health care provided to people with intellectual disability in the large residential setting. In successive reports the Commissioner has been critical of nursing practice, nutritional support, infection control practices and the form of palliative care offered.

Following introduction of mandated annual health checks in three centres, approximately 25 (of 75) young people with spastic quadriplegia in addition to severe-profound intellectual disability have had percutaneous endoscopic gastrostomy (PEG) feeding for periods of 2-10 years.

This paper describes a file review addressing reasons for initiation of artificial feeding, the complications experienced, the nursing protocols utilised and the outcomes of the procedures. The significant dependency of the residents precluded use of conventional quality of life measures. A Nutrition Checklist was used as an outcome measure, as were changes in physical characteristics such as body mass index, bone density and albumin levels. Outcomes such as reduction in frequency of hospitalisation and increase in days spent in the family home were noted. Parents, guardians and nurses involved in the care of the residents were asked for their opinions on their quality of life.

The findings were that most people made gains in physical health. There was some improvement in some psychosocial measures.

There is also now a Policy within the relevant government department that PEG feeding is a medical intervention, insertion of which requires use of an Ethical Decision Making Protocol with all stakeholders having an opportunity to participate.

Nutritional rehabilitation of children with cerebral palsy.

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Introduction: Children with spastic quadriplegic cerebral palsy (SQCP) are commonly malnourished with depleted body fat and protein, and poor bone mineralisation. There have been limited studies investigating the effect of renourishment on body composition in these children.

Aim: to investigate what changes occur in body composition when malnourished children with SQCP gain weight.

Methods: Malnourished children with SQCP were renourished with an enteral formula via gastrostomy tube. Subjects had bone mineral content (BMC), fat mass (FM), and lean tissue mass (LTM) assessed by dual-energy x-ray absorptiometry, and total body protein (TBP) measured by neutron activation analysis pre and post renourishment.

Results: The table shows the preliminary data. Median length of time between measurements was 8.6 months (range 3.7 – 37.0 months).

	Pre-renourishment	Post-renourishment	Percent Change (per cent)
	Median (min, max) (7F, 6M)	Median (min, max) (7F, 6M)	Median (min, max) (7F, 6M)
Weight (kg)	15.4 (6.9, 24.2)	24.5 (12.2, 37.0)*	33.4 (8.51, 96.5)
BMC (g)	469 (264, 711)	597 (266, 953)	22.4 (-0.70, 47.3)
BMC for age (SD score)	-2.6 (-7.9, -1.0)	-2.7 (-8.2, -0.5)	-
FM (kg)	1.8 (0.7, 6.3)	4.4 (1.2, 10.7)*	95.9 (14.9, 464.0)
LTM (kg)	13.0 (5.7, 21.3)	15.8 (8.5, 24.4)	24.9 (5.8, 49.3)
TBP (g) (n=12)	2142 (1072, 3293)	2972 (1232, 6215)	44.2 (-16.5, 122.9)
TBP for age (per cent) (n=12)	48.6 (14.3, 73.0)	54.8 (15.0, 117.0)	-

* Significant change ($p < 0.05$), paired-samples t-test.

Conclusion: Malnourished children with spastic quadriplegic cerebral palsy gain mostly fat mass when renourished.

Day one – Second Keynote Address

Newer treatments for cerebral palsy.

Associate Professor Dinah Reddihough

Royal Children's Hospital Melbourne

Dr Adam Scheinberg and Mr Paulo Selber

Children's Hospital at Westmead, NSW

There have been major advances in the assessment and treatment of children with cerebral palsy (CP) over the past ten years. This update will provide information about the evaluation of the child with cerebral palsy, including the role of brain imaging, metabolic and genetic tests. There is renewed interest in the type, distribution and severity of the motor disorder and this is of relevance to all clinicians as efforts are being made to establish the Australian Cerebral Palsy Register. The treatment of associated medical problems such as poor saliva control and alternate feeding regimes will also be discussed.

Spasticity is the most common tone abnormality seen in children with CP, although many children also have some degree of dystonia. Spasticity and dystonia management are best conducted within a multidisciplinary clinic setting, using goal oriented and objective outcomes. Treatments which are currently used for spasticity/dystonia management include oral medications (baclofen, diazepam, benzhexol), botulinum Toxin-A, intrathecal baclofen pump, selective dorsal rhizotomy and pallidotomy/pallidal stimulator. Most of these treatments are accompanied by prescribed physical therapy programs, and complement orthopaedic interventions required to manage the effects of tone abnormalities such as contracture, and bone deformities.

Orthopaedic surgery has an important role in the management of children with CP. The prognosis for gait as well as gait analysis based treatment options will be discussed. Attention will be paid to treatments that should no longer be used whilst highlighting modern orthopaedic management for these complex patients.

Day one: Session two – Physical Health

The risk factors for coronary artery disease among older adults with intellectual disability.

Dr Robyn A Wallace

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Professor Phil Davidson, Michael Henderson, and Laura Robinson

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Strong University of Rochester, School of Medicine and Dentistry, New York

Coronary artery disease (CAD) is a major cause of mortality and morbidity among older people in the Western world. Risk factors for the development of CAD are well known and health promotion strategies have been developed to address these. Clear guidelines also exist for appropriate medications for established CAD and the risk factors. Presumably the same risk factors for CAD apply

for adults with intellectual disability (ID), notwithstanding that some syndromes of ID are associated with increased risk, and that extreme birth prematurity may also be a risk.

A number of international studies suggest that cardiovascular disease increases with age in ageing adults with ID, though it is not clear whether or not this represents CAD or other heart diseases such as end stage congenital heart disease or cardiomyopathies. Confirmation of a similar prevalence of CAD and risk factors in the ageing population with ID would imply the need to adapt established programs of health promotion to suit this population, and to be vigilant for evidence of clinical symptoms of CAD.

This paper will describe the results of a clinical audit of the prevalence of risk factors for CAD, and diagnosed CAD among adults with intellectual disability aged 40 years and over in Brisbane, Australia. Patient charts will be reviewed for demographic details including etiology of ID and ambulatory status, fasting lipid profile and glucose, HbA1c in adults with confirmed diabetes, blood pressure, body mass index, waist circumference, level of physical activity, smoking status and family history of CAD, confirmed history of CAD, peripheral vascular disease or thrombotic stroke. The prevalence of the risk factors and established CAD will be calculated and the diagnostic and management implications discussed.

Day one: Session two – Epilepsy

Community use of intranasal midazolam for managing prolonged seizures.

Dr Margaret Kyrkou

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Michael Harbord, Nicole Kyrkou, Debra Kay and Kingsley Coulthard

Rectal diazepam (valium), used for two decades, and moderately effective for managing prolonged seizures, has the disadvantages of needing privacy, assembling the kit, removing the person from a wheelchair, and loss of solution with incontinence. Midazolam, a more recently available alternative, has none of those disadvantages.

With students with disability included in mainstream educational settings, staff unfamiliar with seizure management were apprehensive. An interagency Epilepsy Working Party developed a seizure management training package, and a protocol for the administration of intranasal midazolam. Intranasal was more acceptable to school staff than buccal (inside the cheek), additionally the rate of absorption is slightly faster.

In 2004, approximately two years after intranasal midazolam was more widely prescribed for prolonged seizures, and parents and carers were trained to administer it, 347 parents and carers (including school staff) were surveyed. Some completed a questionnaire only, others were interviewed as part of a larger study. Fifty-five had administered rectal diazepam, 70 had administered intranasal midazolam, and 47 had administered both. Thirty-three out of 47 (70.21 per cent) preferred intranasal midazolam, and 39 per cent considered it to be effective within 2 minutes, compared with only 8.8 per cent considering rectal diazepam to be effective in the same time frame.

Of 131 people each given 1-20 doses of intranasal midazolam, seizures were controlled in 95.4 per cent, rising to 97 per cent with increased dose based on weight (0.2-0.3 mg/kg dropped directly into the nose from the plastic ampoule). There were no respiratory arrests (one slowing of breathing possibly due to the seizure), or nasal discomfort post seizure.

Day one: Session two – Nutrition / Cerebral Palsy

Nutritional management in people with developmental disability: the influence of caregivers.

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There is a high prevalence of nutritional disorders in children and adults with developmental disability. While overweight, obesity and constipation are the most frequently seen conditions, under-nutrition, usually associated with dysphagia is also common. Other common nutrition related disorders in this population include conditions such as osteoporosis, specific nutrient deficiencies, food allergies and food intolerance.

Management of these nutritional disorders can be complex, especially in the presence of other co-morbidities and the use of multiple medications. Environmental and social factors also add to the complexity of nutritional disorders in this population. In such a setting, family members and paid caregivers play a crucial role in successful management of these conditions. Factors such as caregiver nutrition knowledge, skills and attitudes, as well as structural and environmental aspects affect the outcomes of management.

At the Developmental Assessment Services, Kogarah, multidisciplinary nutrition clinics are held for children and adults with developmental disability. Using data and case studies from these clinics, caregiver factors associated with the successful management of nutritional disorders in this population will be discussed. Recommendations will be made for implementing effective caregiver strategies in the nutritional management of people with developmental disability.

Day one: Session three – Health Systems

Epilepsy and disability in East Timor – developing a system of sustainable service delivery.

Dr Helen Somerville

Opportunities for community based physical activity for young people with a disability – an overview of international practice and trends.

Ms Kelli Nicola-Richmond

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Young people with a disability deserve the opportunity to participate in physical fitness activities. Research tells us that young people with a disability have less opportunity to participate in community based fitness and leisure activities and that this can have detrimental effects including missing out on the positive physical and psychological effects of exercising. Maintaining fitness, strength and flexibility is important for all people, including those with a disability, in order to allow optimal body function.

The purpose of this study tour was to investigate best practice in the provision of physiotherapy services to young people with a physical disability in the area of providing community based physical activity opportunities.

Currently in Victoria, physiotherapy services for young people with a physical disability are most often delivered within the school environment and within school hours. The government, via the education department, provides funding for the majority of therapy services and it is expected that funding will be used to meet educationally relevant goals. There are limited resources available to provide community based physical fitness activities for people aged 6-18 with a disability.

This study tour provided an opportunity to explore how physiotherapy services are delivered in America and Canada with respect to community based fitness opportunities. A wide range of opportunities for fitness and barriers and facilitators relating to the provision of fitness activities were identified. The information collected during this study tour may be used to assist in improving opportunities for community based fitness activities for young people with a disability within Australian communities.

Neuro developmental outcomes of the Seychelles Child Development Study.

Professor Philip W Davidson

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The Seychelles Child Development Study has prospectively examined over 700 children exposed to MeHg in utero from maternal fish consumption. The study has been double blind since its inception. The mothers averaged 12 meals with fish each week and their mean prenatal exposure was 6.9 ppm in maternal hair. The children were examined five times through 107 months of age using extensive test batteries at each evaluation. The association between over 50 primary endpoints and prenatal exposure was

determined. No consistent pattern of adverse associations was found and these results were confirmed by secondary analyses. However a Benchmark analysis performed on the data from our assessment of the children when they were 66 months of age revealed that we cannot exclude a low risk of adverse effects over the upper range of mercury levels due to the limited number of data points. The study findings will be discussed along with future directions for research on this issue.

Day one: Session three – Human Relations

Working on the margins.

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The provision of accommodation for people with an intellectual disability is a sensitive and problematic topic. It often involves a fine balance between supporting a person's goal to be independent within the community while ensuring the safety of the individual, and in some cases, the community. This is within a community environment that is often resource scarce and sometimes reluctant to include people who are different. Supported Residential Services (SRSs) have been part of the accommodation supports available to disabled or disadvantaged people in the community since the 1970s. For over 30 years, they have provided a supportive environment, where vulnerable people, unable to live by themselves or with their families, could be assured of hot meals, clean clothes, warm beds as well as physical and emotional support. People with an intellectually disability who have associated skill deficits can have complex support needs and be challenging to support within this environment. This paper discusses the results of a review that looks at the complexity of the population of residents with intellectual disability residing in SRSs who often have other health and social problems including psychiatric illness, physical health problems and human relations difficulties. It looks at the impact on support staff, direct carers, GPs, family, case managers and the residents themselves.

Sexuality and disability workshop.

Ms Jennifer Butler and Ms Jennifer Galea

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People with intellectual and developmental disabilities experience the same diverse range of sexual needs and desires as the rest of the community. However, they often have different life experiences that limit opportunities to understand the complexities of human relationships and the rights and responsibilities that encompass sexual maturity.

For people with disabilities and their various carers this particular domain of life skills is seen as a conundrum of complex and divergent problems that rarely has easy answers. It is one that challenges our cultural, moral and ethical mores both as individuals and as a community. It is only in the recent past that specialised services, and to a lesser extent mainstream services have realised

that regardless of a person's developmental disability, sexual development and expression are inherent to the existence and growth of all human beings.

Sexuality covers a broad spectrum of complex issues that includes not only sexual health and development but also the management and expression of feelings, social behaviours, relationships and personal identity. These issues are fraught with a range of differing morals, values and attitudes towards the sexual and emotional development of people with disabilities and often become unnecessarily contentious, given the added stigma associated with disability.

In this workshop it will be demonstrated, through the use of case studies, that what is needed is not a unique approach and that with some adaptations to process, issues regarding sexuality and all that it encompasses can be dealt with in exactly the same way as you would for anyone else in the community. The issues discussed in this session include approaches to educational counselling, the difficulties and dilemmas encountered in service provision and some of the more problematic aspects of sexual behaviour, so let's talk about sex...

Day one: Session three – Dental-Intellectual Disability Interface

Dental care for people with developmental disabilities.

Dr Warren Shnider

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Oral health and dental well-being can only be achieved through a multi-disciplinary approach driven from a medically and dentally informed platform.

The dental needs of patients with developmental disabilities are often ignored or at best poorly understood. Members of the multidisciplinary team must have working knowledge of the normative changes in the oral cavity that appear in unaffected populations, before pathological conditions can be recognized and managed.

Non-dentally trained staff must be able to recognize oral changes and commence preventative measures in the first instance. Where more advanced oral problems are apparent, timely referrals must be made.

Advocacy for medically and intellectually impaired patients must be done with the proficiency that is apparent in kindred medical disciplines.

Dental basics for swallowing and nutrition.

Dr Kerrie Punshon

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Dental problems are an important health issue for people with intellectual disability and impact on swallowing and nutrition. This presentation will cover what health professionals and carers dealing with people with intellectual disability need to know about the basics of common dental diseases and dental caries and what

causes it and the impact of dentition on nutrition and swallowing. We will discuss the role of diet, remineralizing agents, xylitol, oral hygiene and plaque and explain what is erosion, how it differs from dental caries. We will also cover gingivitis and periodontitis, the factors that lead to them and their progression. We will then cover swallowing difficulties, issues with chewing, oral clearance rates, saliva, and what is in saliva when it is aspirated and the difference between healthy microfloras and mature plaque.

We will present research data into the role of oral hygiene in aspiration pneumonia and finish by looking at GORD and dental erosion, medication and saliva, dietary supplements, thickened fluids and the effects on the oral cavity. The presentation will conclude an overview of oral assessments, essential oral health information on the oral health care plan and information to take to a dental visit.

Thegosis – tooth sharpening.

Dr John Chrystie

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The late Ronald Every, proposed a scientific theory, which had been understood in less scientific terms by the Roman poet, Homer. Whereas modern dentistry refers to Bruxism and acknowledges its connection with emotional stress, and refers to it as a para functional phenomenon, Thegosis sees the activity as very purposeful.

The function is to hone or sharpen the teeth, thereby increasing their efficiency as both weapons for fighting and killing and tools for eating. The most convincing evidence of all is in a particular animal model, the wild boar. His lower canine tooth, generally called a task, protrudes from his jaw in the horizontal plane. It is obviously a fearsome weapon. Equally obvious is its uselessness as a chewing tool. The opposing upper tooth is obviously designed to sharpen the lower cuspid. Slides will illustrate these points along with the details of how the Thegotic mechanism works in human beings and the damage which can follow should it become excessive. Applications of the theory will be applied in detail to people with intellectual disability, in terms of behaviour, complex pain diagnosis and limitations of currently available treatments. The concept of oral grooming has a possible role in treatment of people with intellectual disability. Thegosis explains various pains in physical terms – some of these have resulted in people being incorrectly diagnosed as psychotic and some have actually been institutionalised as a result.

Day two: First Keynote Address

Health issues and the policy and practices of disability services.

Mr Arthur Rogers

Disability Services, Department of Human Services,
State Government of Victoria

Day two: Session one – Health Care Delivery

Canadian health care and the health of Canadians with intellectual disabilities.

**Associate Professor Hélène Ouellette-Kuntz^{1,2*},
Dr Deborah Elliott^{2,3}, Dr Tom Cheetham³
and Shirley McMillan**

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The presentation explores the challenges, barriers and possible solutions to the provision of adequate health care for individuals with intellectual disabilities in Canada with a focus on the province of Ontario. Canada prides itself of having universal health care accessible to all. While health care provision is a provincial jurisdiction, national principles set out in the Canada Health Act must be adhered to by the provinces if they are to receive funds from the federal government for these programs.

The legislative framework and funds allocated to health care, has not however meant health for all Canadians. There is now concern that significant health disparities exist and must be addressed by targeting the needs of Canadians most at risk. A review of the international literature and an analysis of Canadian policy and directions informed the identification of challenges, barriers and possible solutions to reduce the health disparities faced by individuals with intellectual disabilities in Canada. Particular attention will be paid to policy issues as they relate to those with both an intellectual disability and mental health problems. Barriers including system factors, physician/health care provider factors, family/other carer or support person factors, environmental factors, and patient factors will be outlined. The presentation will focus on a discussion of system factors and conclude with proposed solutions.

Coordinating to improve health outcomes in people with intellectual disability.

Mr Ron Hyder

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People with intellectual disability have considerable health needs, variable health care and problems with primary health care. Local 'disability support' agencies and organisations in Victoria need to face the challenge of developing a consistent integrated approach to health care by the application of research data.. The Kindilan Society, a medium sized, multi service, disability support agency, sought to address this situation by creating a role for a Community Health Care Coordinator. This initiative aimed to significantly increase the potential for service users to lead healthy lifestyles within a healthy environment through four main foci: (i) Client Health (ii) Community relationships (iii) Staff training and development (iv) Research.

We discuss:-

- The status of the health care support to service users prior to implementation of the role of the Community Health Care Coordinator.

- Barriers preventing or restricting access for people with intellectual disability to quality care for their specific health needs.
- The changes in health care support, since the introduction of the Community Health Care Coordinator's role.
- The intended outcomes and future directions of the role with a view to establishing a 'best practice' model which could be replicated elsewhere in Australia.

Day two: Session one – Carer Health Care Skills

Working together for better health outcomes.

Ms Nicola Chirlain and Narelle Marshall

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This paper will report on the process and outcomes of a project funded in 2004 by the Australian National Training Authority. The project commenced with a regional survey of training needs of staff working with people with disabilities in the New England and North West of NSW. This survey identified the need for staff employed in government and non-government disability services to increase their knowledge of common health issues affecting adults with developmental disabilities, and the need to increase confidence of staff/families when engaging with the medical professions to assist to create positive outcomes for clients/family members. The project involved collaboration with staff from NSW Department of Health, NSW Department of Ageing Disability and Home Care, non government service providers, General Practitioners, allied health private practitioners and staff of a registered training organisation. Collaborative meetings were held resulting in a reviewed general practitioners health check list and pre appointment staff/family assessment process and the development of a Training and Assessment Toolkit to support accredited training from the CHC)2 Community Services Training Package. The Toolkit was developed to ensure effective VET training for staff, in selected units of competency in Certificates III and IV Disability Work. The Toolkit is also useful as a 'stand alone' workshops/training sessions and the supporting health monitoring tools are suitable to incorporate directly into client systems.

Direct care staff's perspectives on meeting the health needs of people with intellectual disability.

Ms Margaret Nicol

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It is of critical importance to provide specialist health care to people with an intellectual disability because the prevalence of syndromes, medical conditions and levels of illness is higher for this group than for those in the general community. Of significance is that direct care staff's level of competence in health care is related the standard of care that will be accorded to clients.

This paper presents the findings of research into the perceptions of direct care staff in relation to their ability to respond to the health needs of people with intellectual disability. The study involved surveying a random sample of staff from Victorian residential facilities with 105 respondents. The results are about staff's

perceived levels of competence and efficacy in this area. The findings also suggest a definite need for staff to explore the special issues which providing health care over the lifespan raises for them. The presentation concludes with recommendations about the educational needs for staff in relation to the health care needs of people with an intellectual disability.

Day two: Session one – Educating Undergraduates

Healthcare scenarios in developmental disability medicine.

Dr Jane Tracy and Dr Mary Burbidge

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This paper describes the development of a teaching tool in Developmental Disability Medicine for undergraduate medical students through a collaboration between the Centre for Developmental Disability Health and the Centre for Learning Technology Support (Monash University)

The CDDHV has a unique role in medical education in our State. Close associations with both medical schools means we provide learning opportunities in Developmental Disability Medicine to all medical students. Our teaching sessions have demonstrated that positive personal experiences with people with disabilities have a powerful influence on students' attitudes and enable them to develop greater comfort and confidence in working with this group of patients. We have, however, found it difficult to provide consistent experiences of this kind to each one of the more than 400 Victorian medical graduates each year. This CD has been developed to complement our teaching by enabling students to 'meet' people with disabilities through an interactive audio visual medium. Extended videos of 'medical consultations' introduce students to people living with intellectual disability, cerebral palsy, down syndrome and dual disability and allow them to observe how challenges are handled in real interactions. The CD has been designed to support the development of positive attitudes towards people with disabilities, and to provide important information in skill and knowledge domains.

Healthcare Scenarios in Developmental Disability Medicine will be showcased and comments and discussion on its content and its use in teaching in medical and other health science courses will be encouraged.

Fitting disability education to meet diverse needs of developing countries.

Ms Judi Moyle

PhD Student

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Dr Teresa Iacono

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Globalisation has created opportunities for Australia to offer education as an export commodity to developing countries in

our region. Malaysia sends many students to Australia for professional and medical training, and Australia has established faculties of some of our major universities in Malaysia. In a preliminary visit to newly established Early Intervention services in Malaysia, the researcher, in her role as a social worker obtained anecdotal evidence to indicate a gap between two major service systems for people with developmental disabilities. Research conducted with parents and service providers provided support for the anecdotal evidence. Further research was conducted with new graduate Malaysian medical practitioners into: (a) their undergraduate training on developmental disability; (b) their attitudes towards the provision of services to people with developmental disability; and (c) other factors influencing their ability to deliver such services in their local communities in Malaysia. In this research, 230 new graduate medical practitioners in their first houseman placement in hospitals in Malaysia completed a questionnaire. Key findings included diversity in training and cultural backgrounds, deficits in knowledge and skills, and time as a factor that limited their ability to provide services to this group. The findings have implications for undergraduate medical curricula in Australia and Malaysia in terms of addressing the diverse social and cultural demands that new graduates will face on their return to communities in developing countries.

Day two: Session one – From Rights to Reality

The right to a healthy life – a perspective from an intellectual disability advocacy organisation.

Ms Helena O'Connell

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More and more, health professionals are working with their patients to achieve better health outcomes. In NSW there are a number of health advisory bodies, including the NSW Health Care Advisory Council. All of these bodies involve consumer participation with a focus towards achieving more patient-centred care. How can this same level of participation be achieved for people with intellectual disability?

NSW CID has long held concerns about the poor health of people with intellectual disability, which is often attributed to their disability and not addressed. In 2000 NSW CID convened a Health and Clinical Services Working Party comprising advocates, health care professionals from a range of disciplines and representatives from the state health, disability and watchdog agencies.

The initial work of the working party was to identify the barriers to good health and to agree on some areas of commonality in terms of goals. In 2002, a directive from the Board of Directors at NSW CID stipulated that people with intellectual disability must be actively involved in all of our work, including our health advocacy. This led to a highly successful seminar (co-hosted by NSW CID and the then Community Services Commission) called the Right to Good Health, where people with disability presented some of the material and participated in workshops.

In summary the presentation will outline some of the strategies for effective advocacy for and with people with intellectual disability and the benefits to health professionals and workers in working with advocacy organisations.

Health assessments: where to from here?

Associate Professor Nicholas Lennox

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The presentation will consider the historical basis for the introduction of health assessments in the general population and subsequent implementation in the elderly. Some of the challenges faced by researchers and policy makers when deciding how to interpret the vast geriatric screening data will be examined.

The evidence that prompted the investigation of health assessment in people with intellectual disability will be discussed along with the results of health assessment studies. The outcomes of these studies will be compared to other approaches which seek to improve health in this population, such as specialist review and personal health records. This will lead to suggestions of the strategies which may result in improvement in the health of adults with intellectual disability. Observations on how we should proceed and what it would take to gather the evidence will be presented.

Poster in the foyer

A health promoting approach to osteoporosis prevention for people with a disability.

Ms Sue Milner

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People with a disability experience poorer health outcomes in comparison to the general population. Preventable lifestyle diseases and conditions are commonly diagnosed and it appears that mainstream health promotion efforts are not reaching this population sub-group.

In 2004, the Disability Services Division of the Victorian Department of Human Services introduced a strategy to increase the awareness of the high risk of osteoporosis for people with a disability. Poor dietary practices, limited capacity for physical activity, inadequate exposure to sunlight and high prescription rate of medications known to be associated with reduced bone density, are key contributing factors. Targeting people with a disability and carers/support workers, the Strong Bones strategy aims to encourage positive change in lifestyle factors. A series of information resources including a video, fact sheet, booklets, stickers and fridge magnets were developed and introduced to government-managed shared supported accommodation facilities in Victoria, initially reaching approximately 3700 people with a disability and 5500 direct support workers. The resources have been developed within a disability context, are inclusive of the communication needs of people with a disability and can be accessed via the Disability Services website. Evaluation of this strategy was via an electronic questionnaire sent to government-managed supported accommodation facilities. Change in lifestyle practice of individuals and details of how this strategy has been embedded into the quality improvement processes within the accommodation facility were key evaluation indicators.

Day two: Second Keynote Address

The relationship between quality of life and health outcomes in people who have an intellectual disability.

Professor Robert A Cummins

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This paper will explore the relationship between life quality, health, and disability. In particular it will challenge the construct of Health Related Quality of Life which confuses medical and psychological symptoms of ill-health with life quality. The problems created by this include: (a) The creation of a tautology, where disability or illness define life quality; (b) The assumption that the absence of disability or illness equates to high life quality; (c) The supposition that physical health has a linear relationship with perceived life quality. I will argue that each of these propositions is either discriminatory or false. An alternative conceptualization will be presented in which medical symptoms are largely independent of people's regard for their general life quality. This global perception, in the form of subjective wellbeing (SWB), is now firmly established within the psychological literature. Most notably, SWB is controlled by homeostatic processes which endeavour to keep people feeling positive. Thus, in a manner analogous to the physiological homeostatic systems, the SWB of each individual person is normally maintained within a narrow range of values. Homeostasis explains the generally weak relationship between SWB and medical symptoms. The implications of this system for quality of life measurement will be discussed. The Personal Wellbeing Index will be introduced as a generic measure of SWB and one that has been adapted for use by people who are cognitively impaired. It will be concluded that HRQOL measurement should be abandoned in favour of the separate measurement of medical symptoms and subjective wellbeing.

Day two: Session two – Advocacy and Health Professionals

Genetic Health Services Victoria and Genetic Support Network Victoria – partners in improving services for families with genetic conditions.

Ms Susan Fawcett¹, Professor A Bankier¹, Ms L. Lonsdale², Mr T. Briffa², Ms R. Forbes¹ and Dr M. Aitken³

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Genetic Health Services Victoria (Genetic Health) has had a close relationship with the Genetic Support Network of Victoria (GSNV) since 1999, united in a common goal to improve clinical services, support and advocacy for families with genetic conditions.

Genetic Health is committed to providing a consumer focussed clinical service. Mechanisms were developed for GSNV participation in service development to ensure that a consumer focus was maintained through the process.

Genetic Health undertook a process of strategic planning which included members of GSNV, through a number of community consultants. This led to the formation of consumer focus groups to determine needs for client centred genetic services current and future.

The outcomes of these were written into a consumer feedback questionnaire, which is being piloted at some Genetic Health clinics and will be implemented across all clinical services. This enables monitoring of consumer satisfaction and ongoing improvement.

Other outcomes include;

- development of a patient information brochure,
- identification of consumer focused quality measures,
- a transparent and outcome driven grievance procedure,
- commencement of an advocacy project.

Genetic Health and GSNV continue to work together toward their common goals. Their proximity allows regular communication and a close working relationship. GSNV continues to play an integral role in Genetic Health strategic planning, and a Genetic Health representative remains a member of the GSNV board.

A specialist medical practice in developmental disability in Australia – the rehabilitation medicine perspective.

Dr Lynette Lee

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Since 1976 Rehabilitation Medicine has been recognised in Australia by the Health Insurance Commission as a Principal Specialty. The Australian College of Rehabilitation Medicine was formed in 1980 and in 1992 the College became a Faculty of the Royal Australasian College of Physicians. The training scheme requires development of competence in musculoskeletal, neurological, orthopaedic, urological, gastro-intestinal, behavioural and psychological medicine and sub-specialties have evolved in spinal, amputee, stroke and brain injury care as well as cardiopulmonary and geriatric rehabilitation.

This presentation will profile the last hundred cases of adults with intellectual disability referred to a Rehabilitation Physician (Physiatrist) in a city practice in Australia. The majority of cases were people with severe-profound intellectual disability and spastic quadriplegia from congenital disease, trauma or genetic predisposition. The referrals sought assistance with management of musculoskeletal physical health and particularly spasticity. A small number have been referred for diagnosis and management of behavioural disturbance. All cases have required a comprehensive approach and involvement of a team of medical, nursing and allied health professional practitioners with regular case conferencing and follow up.

Some cases with typical 'rehabilitation medicine' problems will be highlighted and their outcomes discussed.

When adults with intellectual disability need to go to hospital: improving the experience and outcomes.

Dr Robyn A Wallace

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The European Manifesto for Healthcare implies that a core group of specialists in intellectual disability healthcare should be available within generic services to assist health professionals care for adults with ID. A brief review of the literature on utilisation of hospitalisation, barriers to delivery of service in the hospital setting, and results of a recent survey of hospital-based professionals doctors' and nurses' attitudes in the hospital setting regarding the healthcare of adults with intellectual disability will be presented.

Ingredients for workable systems of delivery that appear work in the hospital setting will be reviewed. In particular un-trialled but sensible speculations about necessary logistical elements of hospital based service, preparation from the patients' side and consent issues will be discussed.

The metabolic social worker goes into bat – a case study in advocacy.

Mrs Flora Pearce

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Social Work Role within a multi-disciplinary team

This clinical presentation will highlight one particular aspect of the social work role within a multi-disciplinary treatment team.

It will focus on a metabolic patient in her final year of secondary education. This patient used all the available channels within the Education system to be given due consideration for her medical disadvantage. However the system let her down.

The social worker explored other avenues of representation as well as encouraged and supported the patient and her family not to be defeated by the illness and the 'system'. The psychosocial care is a critical element of the medical treatment and must always be provided for, especially during times of tightening budgets.

Day two: Session two – Physical Health and Quality of Life

What about me?

Ms Penny Kendall

Manager Community Living Support Services, Melba Support Services
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Ms Denise West

Speech Pathologist, Communication Resource Centre
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This paper will present the story of a 34-yr old man who has a severe intellectual disability, congenital hypotonia, and autism. "Tom" has a

great quality of life. He enjoys his own company and will also engage with familiar people including housemates and staff.

In February this year "Tom" choked while eating a sandwich which led to a subsequently cardiac arrest. He presented at hospital as unconscious and unresponsive. He was sedated and placed on life support on admission to hospital. His medical condition was critical, and staff were advised by the registrar in the emergency department to turn off life the support. The residential staff refused to follow this recommendation and "Tom" was transferred to another hospital due to a shortage of intensive care beds.

"Tom" is now living back at home and attending his day programs. He has made a remarkable recovery and is eating and drinking modified textures.

This presentation will discuss the issues concerning quality of life and the perception often made by the medical profession that a person with an intellectual disability is less deserving than the general community for intervention and services.

Gastrostomies – improving quality of life?

Ms Lyn Tatt and Ms Hilary Johnson

Gastrostomy Information & Support Society (GISS),
SCOPE (Vic)

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More people with disabilities and complex health needs are living in the community. In NSW mortalities among people living in residential services has led to a coordinated approach to addressing the needs of people with mealtime issues. (Community Services Commission 2002) There are an increasing number of people with disabilities who die from aspiration due to problems with eating and drinking. (Hollins, Attard et al. 1998)

In Victoria the need for people to receive nutrition through an alternate route, usually with the insertion of a gastrostomy has been recognised and equipment funded through the Home Enteral Nutrition Service (HENS) program. However for people living and aging in accommodation services this adds to the care issues for families, clients and staff. Extra tasks need to be completed within establishment hours and with no additional funding. GISS, a support society for people with gastrostomies, their families and professionals founded in Victoria in 1990 has been receiving increasing requests for guidance around several issues which impact on a persons quality of life.

This presentation will focus on the questions of developing best practice guidelines to ensure adequate health care, obtaining informed consent by people with intellectual disabilities and training for staff to support people to live quality lives in the community. One of the remaining challenges is ensuring people with intellectual disabilities receive the same information and choice as people without disabilities in the hospital sector.

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Feeding related quality of life in children with quadriplegic cerebral palsy: health professionals perceptions.

Dr Angie M Morrow

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Aims: 90 per cent of children with quadriplegic cerebral palsy (QCP) have difficulties with feeding due to impaired swallowing. Our aim was to examine health professionals' (staff) opinions on the major determinants of feeding related quality of life (QoL) in children with QCP.

Methods: A trained facilitator conducted 5 semi-structured focus groups during September and November 2003. Participants (staff, n=45) were recruited through two paediatric university teaching hospitals in Sydney and included paediatricians (n=18), nurses (n=15) and allied health professionals (n=13). The response rate was 77 per cent. Recruitment ceased when informational redundancy was reached. N-Vivo software was used to analyse transcribed audiotapes.

Results: Participants thought the QOL of child and parent were inseparable and that domains could not be ranked as their relative importance would vary between families. They believed physical well being (e.g. physical comfort, nutrition), parent-child interaction (e.g. burden of care, emotional impact), social participation (eg. sharing meals, social acceptability), the child's emotional well being (e.g. happiness) and delivery of health services (e.g. access to services, interaction with staff) were contributing factors. Parent child interaction, delivery of services and physical well being were the most common topics, this finding did not differ across disciplines. Allied health professionals were more likely than physicians or nurses to identify child's emotional well being and socialisation as being important.

Conclusions: Staff felt that parental and child QOL were inseparable in children with QCP. Parent-child interaction, communication and physical functioning emerged as important themes. This has implications for design of QOL tools and clinical practice.

Feeding related quality of life in children with quadriplegic cerebral palsy: Parental perceptions.

Dr Angie M Morrow

The Children's Hospital at Westmead
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Aims: Up to 90 per cent of children with quadriplegic cerebral palsy (QCP) have feeding problems due to impaired swallowing, most commonly treated with gastrostomy tube feeding. Our aim was to identify parents' opinions on the major determinants of feeding related quality of life (QoL) in children with QCP.

Methods: Participants were recruited from parents of children attending a specialised feeding clinic in a paediatric teaching hospital in Sydney. 24 parents participated in 4 semi-structured focus groups conducted by a trained facilitator. Recruitment ceased when informational redundancy was reached. Transcribed audiotapes were analyzed using N-Vivo software.

Results: Parents felt that the QOL of child and parent were inseparable. They identified social participation, parent-child interaction, the child's emotional well being, physical well being and delivery of health services as contributing to their child's QOL. Social participation emerged as a strong theme. Parents of children with and without gastrostomy differed in their perceptions. Parents who favoured gastrostomy believed they had mistaken hunger for enjoyment of food and saw reduction in time spent feeding as the most positive outcome of gastrostomy. Parents of children with gastrostomy were more likely to be dissatisfied with interaction with staff. Communication difficulties with health professionals (e.g. feeling they were not being listened to) impacted on decision making processes regarding interventions.

Conclusions: Social participation and parent-child interaction emerged as strong themes. The pattern of priorities identified differs from those identified by health professional in previous studies. These findings have implications for design of QOL instruments and clinical practice.

Day two: Session two – Health Care Delivery Systems

Measuring the effectiveness and outcomes of Victorian school programs for students with a disability.

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This presentation outlines a recent project commissioned by the Victorian Department of Education and Training that aimed to develop an accountability framework for students with disabilities within all government schools. The first phase consisted of a review of the international literature and other countries accountability systems and resulted in a performance framework that consisted of 63 possible indicators that explored the effectiveness of school processes and outcomes for students (aged 5-18 years) with disabilities.

Ten statewide consultations forums were held between February and April 2004. School principals, assistant principals, integration coordinators, teachers, parents and allied health professionals attended the forums. The aim of the consultation process was to; gain feedback on the proposed indicators, their relevance to the Victorian education system and the diverse range of student disabilities; and, to identify the most important and useful indicators. During 2004, the refined set of indicators was used in a trial with 15 primary, 15 secondary and eight special schools. Indicators included program inputs, school processes and student outcomes. The findings of this project are presented.

Access Assistant Program: providing invasive health care in educational settings.

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The Access Assistant program works in partnership with health services, education sectors, and disability services to safely support

students with disability and invasive health care needs in educational settings in South Australia.

Founded in 1993, initially Health Support Officers (HSOs) provided personal care support in two large educational settings attached to residential services. Registered nurses carried out any invasive care procedures.

Registered nurses now train individual Health Support Officers (carers) for specific health care tasks including managing tracheostomies, oxygen, suction, tube feeds and catheterisation. The Program currently employs 65 HSOs to support 110 students with invasive health care needs in 47 preschools and schools across South Australia.

In collaboration with Department of Education and Children's Services staff, we have helped develop standardised health support plan proformas to be signed by the doctor and parent, for management of first aid and non-invasive conditions such as anaphylaxis, asthma, epilepsy, and cystic fibrosis. There are also support plans for meal time management, transfer and positioning, and continence care. Booklets have also been written to provide more information on each condition. More recently under the auspices of the Disability Services Office these proformas are being converted to generic to cover all ages and settings, with the intention that one person will carry the same plan for all settings accessed.

Recently, the model has been expanded in a Delegated Care Program to support children in long day care, family day care, out of school hours and vacation care.

A comparison of Australian and UK psychiatry training and services to meet the mental health needs of adults with intellectual disability.

Dr Jenny Torr¹, G Jess, Professor S-A Cooper, Associate Professor N Lennox, N Edwards and G OBrien

¹ Centre for Developmental Disability Health Victoria, Monash University

Aim: Compare the views of fellows and trainees of the Royal Australian and New College of Psychiatrists practicing in the State of Victoria, Australia with members of Faculty of Learning Disability of the Royal College of Psychiatrists, United Kingdom regarding psychiatric care of adults with intellectual disabilities.

Method: Postal survey using a modified version of the self administered questionnaire developed by Lennox and Chaplin (1995) to assess the perceptions of psychiatrists and trainees in Victoria. The questionnaire employed 34 likert-scaled items to assess views on the role of psychiatry in intellectual disability, assessment and management, adequacy of training and professional confidence in managing mental health needs of adults with intellectual disabilities.

Results: The Australian response rate was 225/840 (27 per cent) of UK response rate of 329/486 (68 per cent). In comparison with the UK specialists in the psychiatry of intellectual disabilities Victorian psychiatrists and trainees lacked confidence and considered their training inadequate in meeting the mental health care needs of adults with intellectual disability. Australian and UK respondents though people with ID received poor care in generic mental health services.

Conclusion: These findings highlight the importance of specialist training and services in meeting the mental health needs of people with intellectual disabilities.

Day two: Session two – Targeting Intellectual Disability Populations

Lost in transition – issues of transition to adult health care for young people with developmental disabilities.

Ms Felicity Sloman

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A growing number of young people with developmental disabilities and/or complex medical needs are surviving to young adulthood and beyond, partly as a result of significant advances in medical science, practices and technologies. Transition to adult health care is increasingly understood to be an essential aspect of paediatric practice and is considered a major milestone in the life of most young people and their families. If well planned transition processes are not created, young people are likely to experience an ad hoc, ill prepared transfer to adult care. The consequences of this is an increase in the rate of young people dropping out of the health care system soon after transfer to adult care, often not re-entering the system until they require emergency intervention. Many preventable exacerbations of their condition could be avoided by regular review with appropriate and timely intervention.

Currently, many young adults with complex disabilities continue to receive their care at the Royal Children's Hospital (RCH) beyond the point at which it would be appropriate for them to access adult hospital services. Attempts to transfer them to adult services in some parts of Melbourne had been difficult because those facilities were either unwilling or unable to accept these young adults. There was thus a need to identify adult sites with the skills and willingness to develop clinics for young adults with developmental disabilities. In November, 2004 a Project was commenced at the RCH, Melbourne. This presentation will outline the issues, the new clinics, the challenges and the future plans.

Evaluation of family-centred care for young children with intellectual disability in Western Australia.

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Introduction: Early intervention (EI) services for children with intellectual disability (ID) in WA have endorsed the model of family-centred care. This study aims to evaluate how well these services practice family-centred care.

Method: The study included children aged 0-5 years with ID, who were registered clients of Disability Services Commission, WA. Parents completed a mailed survey questionnaire, which elicited demographic information, the frequency and type of services received and parental perceptions of services using the Measure of Processes of Care (MPOC) questionnaire. The MPOC includes five domains – “Enabling and Partnership”, “Providing general information”, “Providing specific information”, “Coordinated and Comprehensive Care” and “Respectful and Supportive Care”. Item

scores range from 0 to 7 indicating least to most satisfaction. Mean scores for the five domains were compared using ANOVA against the independent variables of child age group, service type and frequency, place of residence, family and demographic variables.

Results: Of 292 eligible families, 165 (59 per cent) returned a completed questionnaire. While over 50 per cent of children had contact with occupational, speech and physical therapists at least once per month, less than 20 per cent of children had at least annual contact with either psychology or dental services. MPOC means ranged from 4.0 (SD1.7) for “Provision of general information” to 5.8 (SD 1.1) for “Respectful and supportive care”. Higher means were associated with metropolitan residence, higher parental educational level and more frequent contact with allied health professionals.

Conclusions: Overall EI services for young children with ID in WA demonstrated satisfactory practice of family-centred care, except in the “Provision of general information”. However, there is a need to improve the processes of care for rural families and those with lower parental educational level. The study also highlights unmet needs in dental care and psychology services for this vulnerable population.

Early outcomes from a population-based intellectual disability database in Western Australia.

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Despite improved socioeconomic status, advances in medical care and technology and increased life expectancy, we have yet to see a decline in the incidence of outcomes such as intellectual disability in Australia. The principal aim of the Western Australian (WA) Intellectual Disability Database now known as IDEA (Intellectual Disability Exploring Answers) is to provide an infrastructure for population-based epidemiological research into the causes and prevention of intellectual disability (ID) as well as research into the health status and service needs of children and adults with ID.

This presentation will provide results on three recent research investigations undertaken using this database and its linkages to other WA population databases. It will report on our findings in relation to the socio-demographic determinants of ID where we found that children of the most socially disadvantaged, Aboriginal, teenage and single mothers were all at greater risk of mild-moderate ID. It will report on the relationships we have found with maternal health and ID where for example we have found that children of mothers with epilepsy are particularly at risk of mild-moderate ID and those of mothers with anaemia of severe ID. Finally it will describe the patterns of hospitalisations in the first five years of their lives for WA children with ID.

Day two: Session three – A Systems Perspective on Health Services

Individual planning for healthier outcomes in the community.

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The Disability Services Division of the Victorian Department of Human Services (DHS) is currently introducing Individualised Planning & Support (IP&S) and building more inclusive communities through its RuralAccess and MetroAccess initiatives.

Based on overseas experiences of similar approaches, Individualised Planning & Support (IP&S) involves the person with a disability directing their own life as much as possible, with access to a range of flexible supports.

With the support of a facilitator, or planner, people identify their particular life goals and work out a plan to achieve these goals. The plan considers people's individual abilities, aspirations and needs within their network of family, friends and community, and identifies the range of the supports necessary to make the plan work. While the plan often includes government-funded support, it also focuses on wider and more community-oriented options and improved health and well-being outcomes.

None of this is possible without paying attention to the community context within which individual planning and health outcomes are taking place. Based on the principles of community building, RuralAccess and MetroAccess work to harness the strengths, resources and creativity of individuals and communities to enhance the community membership and participation opportunities for people with disabilities. Both initiatives are working in combination with an increasingly individually focused planning effort to build more supportive and inclusive communities where better health outcomes are possible.

The presentation will provide an overview of the Individualised Planning & Support approach and the RuralAccess and MetroAccess initiatives to date.

Meeting the medical needs of adults with developmental disabilities in an inclusive system.

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Until late last century disability services in Victoria were provided by segregated, mostly large residential facilities. Doctors and other health professionals were employed to work within these facilities. Changes to more integrated and more community-based service models followed a major review in 1977.

In addition the system was accustomed to reduced life expectancy. By the 1980's it was becoming apparent that survival to middle and late adulthood for people with developmental disabilities was to be expected.

This led to changes in the way service systems were delivered. Large training centres were closed; community-based services were developed; and it was acknowledged that responsibility for services extended beyond disability services in other areas such as Housing, Education and Employment.

In Health, Disability Services restructured their resources so that the money previously used to employ doctors in the residential Training Centres was used to create, in 1991, two academic units responsible for enhancing the care of adults with developmental disabilities in the community. The Department also established a medical committee to monitor the health care of all its residential clients. The last annual report of the Committee provides, some insights into the ongoing needs of this population.

The Committee has noted many improvements in the care of this population, particularly in the areas of quality of life, but has ongoing concerns about some aspects of health care, particularly energy of management and availability of specialist medical services.

What to do about health disparities among persons with intellectual disabilities: some US strategies combining a public health and clinical approach.

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The absence of a national health system or any form of universal health insurance in the United States has led to a variety of approaches and strategies to ensure access to health care for persons with intellectual (or developmental, U.S. term) disabilities. A new program at the School of Public Health, New York Medical College and the Westchester Institute for Human Development – the Center on Health and Disability – combines academic and clinical agendas to address the persistence of health disparities among persons with intellectual disabilities.

People with intellectual disabilities have not shared in the significant advances in knowledge and technology that have contributed to the health and longevity of the population. This paper will discuss how this new Center for Disability and Health plans to translate advances in the informational, assistive, and biomedical technologies to promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the United States. It will focus on strategies for improving access to health care, shifting the clinical focus to health promotion and prevention, and the critical leadership educational role that must be played if promising clinical practices are to become the source of systemic change.

Day two: Session three – Innovations in Health Education

Does the written information make sense? Achieving better health outcomes by developing accessible written information.

Ms Katie Lyon for Ms Cathy Basterfield

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We all need written information that we understand. A lot of information we receive is through printed material. There is often a lot of jargon and technical terms used. Many people with developmental disabilities have difficulty understanding and using written information. Developing written information that is understandable and accessible enables the person to understand the information, be included in decisions about their own health and to make meaningful choices and then access appropriate services. There are many issues that need to be considered in developing accessible written information for individuals. Generic documents, forms and brochures also need to be reviewed to ensure everyone is able to access written materials in a way that is meaningful. These issues and examples will be discussed in this paper.

A website about diabetes for adults with intellectual disability – development and evaluation.

Ms Therese Rey-Conde, Professor N. Lennox and J McPhee

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Objective: To provide a tool for people with diabetes and intellectual disability to improve the education in diabetes and management of health care for them and their carers.

Methods: We describe the development of a web site to improve the knowledge and management of diabetes in the area of intellectual disability. The design process was collaborative with adults with intellectual disability, carers, and professionals (n=76) in 39 focus group discussions. We wanted to qualitatively explore issues that are important to people living with diabetes and intellectual disability. Then we wanted to present the relevant information in an easy-to-use format. We based the content of the website primarily on the findings from those discussions, and secondly on evidence from the literature. The material to be included was reviewed by an endocrinologist, a general practitioner, several diabetes educators, occupational therapists, nurses, nutritionists, podiatrists, service managers, a pharmacist, and a clinical biochemist. All material used was evidence based. To format the site we employed a graphic artist experienced in work for this population. A speech therapist also gave advice and an editor reviewed the final work. We aimed the tool at the two principal groups - the people themselves and their carers. For the people with intellectual disability we produced a site consisting largely of graphics and images - it addresses 14 areas of relevance. For the carers the tool addresses most of the education and management issues expressed as being of interest to them in the focus groups.

To make sure the site was user-friendly we involved end-stage users and professionals in all stages of the development process. We ran a trial of the tool for one month with a group of 21 carers and 6 people with both intellectual disability and diabetes.

Results: The final design is the educational web site to be found at www.uq.edu.au/diabetes. Preliminary results are promising and the site is receiving about 450 hits per month. The site was well accepted by both people with intellectual disability and their carers, as expressed in interviews with them. One third of carers changed their behaviour in a wide range of areas of diabetes care after a short trial of the intervention. These changes were small, but consistent.

Conclusion: This site may fill a need in this group of people with few resources. The consultative process that we used resulted in a unique tool for patient education. We hope to use similar processes to develop more sites for people with intellectual disability in other health areas that are of high relevance to them.

Practice Implications: This material could be of interest to any people with low literacy skills because of the graphics-based design. It is very importantly of low cost to the consumer; it is empowering and has the potential for a more interactive format in the future.

Acknowledgments: The National Diabetes Improvement Program from the Commonwealth Dept of Health and Aged Care, and the Queensland Centre for Intellectual and Developmental Disability both funded this project.

Better Health Channel articles: information made easy.

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The Victorian Department of Human Services (DHS) provides a range of services for people with disabilities. Disability Online (www.disability.vic.gov.au) is a web site that provides people with a disability, their families and carers with access to online information. The site includes a service directory, an events calendar, useful links to a wide range of websites for people with a disability and articles on a wide range of disability and health related topics. These are shared with the Better Health Channel web site (www.betterhealth.vic.gov.au).

In 2004, the DHS engaged the Communication Resource Centre, Scope, through their Communication Aids and Resource Materials (CARM) service, to assist in translating approximately 100 of the Better Health Channel articles into Easy English. This would ensure people had access to online information in a format that could be easily understood.

Easy English is defined as information that is summarised and expressed in short sentences that each convey a single idea or concept. Ideas and information are expressed without jargon and in clear terms. Illustrations are also often used in this format (Manton, J. et al. 2003). People who benefit from Easy English include young children, people with an intellectual disability and

people from culturally and linguistically diverse backgrounds. The use of pictographs can add meaning to the written text to make concepts easier to understand. According to the literature, illiteracy levels among people with disabilities range between 50 – 100 per cent (Koppenhaver, D. et al. 1995).

The articles that were translated included topics such as acquired brain injury, asthma, depression, nutrition, smoking, men's and women's health and grief and loss. This paper will present an overview of the health related articles translated, the different formats that are now available and discuss how these resources will enhance health outcomes for people with disabilities.

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Day two: Session three – Improving Access to Health Services

Improving access to National Health Service Walk-in Centres for people with learning disabilities.

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This presentation will be a report on work in progress. The aim of the research project is to create learning opportunities for staff from National Health Service (NHS) Walk-in Centres in Bristol, England that will enhance their responsiveness to the needs of people with learning disabilities. *Valuing People* (Department of Health 2001, p.60) stated that improving access to mainstream services was the most important issue that the NHS needed to address for people with learning disabilities. Discussions involving carers and learning disabilities nursing tutors indicated that enhancing the responsiveness of Walk-in Centres would make a worthwhile contribution to improvements in access to primary care services. Consultation with the Clinical Manager of the Walk-in Centres led to an exploration of the learning needs of staff in the Centres and established a mutual interest in developing teaching and learning strategies that would build on their existing knowledge and enhance their confidence.

Working in conjunction with Bristol People First lecturers from the University of the West of England have developed workshops that will be jointly delivered to staff in the Walk-in Centres. Research will evaluate the impact of sessions delivered by tutors and facilitators from People First.

The workshops aim to improve services delivery by fostering and supporting closer working relationships between people with learning disabilities, primary care providers and learning disability nursing practitioners.

Reference

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Why are some adults with an intellectual disability more difficult to provide services to?

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In recent years it has become evident that disability have difficulty in providing services to a small but costly group of about 150 people. This group presented with a range of difficult behaviours that required additional human resources to manage risk issues. The Victorian Dual Disability Service undertook an assessment of the mental health of a sample of this population to explore the hypothesis that an unidentified mental disorder was contributing to the difficulties in providing a service. The methodology consisted of identifying a sample of 50 and performing a comprehensive mental health assessment. The findings supported the main hypothesis and identified the types difficulties that services were experiencing. The reasons behind these findings are explored in relation to the process of deinstitutionalisation and the nature of the mental disorders found to be present.

Living with a disability.

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The services that people with disability and their families use are many and varied with different funding sources and variable inter-service communication. The complexity of these services and their interaction is often difficult to grasp both for parents and professional support staff. Having an overview of this process helps clinicians to maintain perspective in their management. Teaching this to undergraduate medical students has been helped by the use of a model I have developed that explores where these services are needed in the context of a person's life. This facilitates an understanding of the consequences incurred by that service being unavailable or inaccessible.

Day two: Session Three – Health and Quality of Life

A quality of life scale for children with cerebral palsy: QOL from the perspective of families.

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Purpose: To develop an international condition-specific quality of life (QOL) scale for children with cerebral palsy.

Introduction: A condition specific QOL scale for children with cerebral palsy is being developed to evaluate the effectiveness and impact of treatment interventions in clinical trials. The measure's content is based on determinants of QOL, reported by children with cerebral palsy and their parents.

Methods: Semi-structured interviews were conducted with 28 parents and 13 children with cerebral palsy to identify the major themes of QOL. Parent-proxy interviews were conducted for children aged 4-8 years, and parent-proxy and child-report interviews were conducted for children aged 9-12 years.

Results: Data were analysed to provide thematic summaries, and specific items were derived to measure each domain of QOL through consulting with researchers, clinicians and parents. The items aim to measure several domains including physical health, body pain and discomfort, daily living tasks, participation in regular activities, future QOL, emotional wellbeing and self-esteem, family health, financial stability, provision of, and access to services, supportive physical environment, social wellbeing, communication, and interaction with the community.

Conclusion: The resulting QOL scale for children with cerebral palsy includes the traditional domains of QOL such as physical, emotional, social, and family health. It also includes more practical domains such as access to care, financial stability, use of equipment, and acceptance into the broader community. Methodological issues relating to scoring and evaluating the child report and parent-proxy questionnaires will be discussed.

Promoting health of families with children with disabilities: A health mentoring project.

Ms Linda Goddard and Ms Sandra Mackey

Associate Professor Patricia Davidson
and Professor John Daly

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Project description: There is growing evidence that caring for a family member with a disability is linked to an increase in mental and physical health problems for the caregiver. Nursing lecturers at Charles Sturt University Albury have initiated a health promotion project aimed at enabling mothers and other family members of children with disabilities to increase control over and to improve their health. Third year undergraduate Bachelor of Nursing students are working collaboratively with their lecturers and local families to identify and address the actual and potential health needs of these families.

Aims: Through taking a partnership approach the aim is to develop personal skills in the mothers and family members which assist them to manage their health, enhance wellbeing and generate social capital in the community of families with children with disabilities. In addition, nursing students will develop the professional skills for building social capital and community capacity which are vital if health care workers are to take a primary health care approach to practice.

Outcomes and emerging challenges: This is the first phase of a project which will develop a prototype health mentoring program that can be utilised in other settings and health education contexts to increase community capacity and empower families with children with disabilities through education and access to resources.

Project successes will be seen in the empowerment of families involved in the project, and theoretical and practical knowledge development in future health care workers who might otherwise maintain a biomedical approach to health care.

The role of direct support workers in health care for adults with intellectual disabilities.

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There continues to be widespread concern about health care provision and the poor health status of adults with intellectual disabilities (ID). Although it is acknowledged that many adults with ID are reliant on their support workers to initiate and maintain the appropriate use of primary health care services, research into improving health care for this group has focussed primarily on general practitioners. The aim of the current study was to investigate (a) the use of community health services by support workers for adults with ID, and (b) the factors that promote and restrict appropriate use. Given the lack of prior research in the area, qualitative research was adopted using methods of grounded theory. Variables of importance and hypothesis were generated from data collected by way of semi-structured interviews with support workers employed in community houses. Preliminary results provide an insight into how support workers' viewed their role, and that of the medical profession, in health care for adults with ID. The impact of these findings on the practices of support workers and their aim to achieve positive patient outcomes will be discussed in the context of the Australian health and disability sectors.

Day three: First Keynote Address

Progress report on the findings of the Senate Standing Committee on Mental Health.

Senator Lyn Allison

Australian Democratic Party

The evidence base for mental health outcomes for people with developmental disability.

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Mental ill-health and problem behaviours are prevalent amongst adults with intellectual disabilities. This is likely to relate to biological, psychological, social, and developmental aetiological factors, although the evidence base for understanding such associations is limited. This presentation contributes to existing knowledge by presenting new data on mental ill-health prevalence and incidence, and associated factors, for a population-based cohort of over 1000 adults with intellectual disabilities.

The clinical implications of our knowledge of behavioural phenotypes.

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The phrase 'Behavioural phenotypes in organic genetic disease' refers to the fact that a particular behaviour may be as characteristic of a syndrome as the physical phenotype. It is now recognized that specific cognitive profiles or patterns of maladaptive behaviour and/or psychiatric disorder may vary depending on the specific cause of the intellectual disability. This observation, taken together with functional psychological models based on learning theory, has led to a more sophisticated understanding of such behaviour acknowledging both environmental and biological components. From a clinical perspective it is the identification of developmental, biological, psychological and social factors that predispose to, precipitate, or maintain the occurrence of psychiatric or behaviour problems that guides intervention. In clinical practice such an approach often requires a multi-disciplinary perspective and the integration of different models of understanding. A detailed longitudinal history, information from informants, direct observation, and sound mental state and physical assessments will all contribute to the diagnostic process and formulation. The strengths and weaknesses of this concept will be examined with particular relevance to Prader Willi Syndrome and associated maladaptive behaviours and psychiatric illness.

Day three: Session one – Behaviour Phenotypes

Rett syndrome research in Australia and internationally – past, present and future.

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The Australian Rett Syndrome Database is a population-based study of ~280 Rett syndrome cases born since 1976. The current aims of the study are to describe the natural history of the disorder and assess its impact on resource utilisation and the economic and social burden on families and the community. Baseline data on communication, mobility, symptoms and classification are collected on case enrolment. Follow-up data on functional ability in daily living, behaviour, hand function, medical conditions, and use of health and education services are collected every two years and on carer health and well-being every four years. Molecular testing has been completed on over 80 per cent cases. This presentation will provide up to date Australian information on the epidemiology and genetics of Rett syndrome and on the international Rett syndrome project being conducted from Western Australia. It will also provide an overview of recently undertaken and published research much of which has focussed on the clinical variability and the relationships between genotype and phenotype.

Update on Fragile X Syndrome (FXS).

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Fragile X syndrome (FXS) is the most common known inherited cause of developmental disability. Affected individuals of both genders at all ages present with a wide range of physical, developmental and behavioural characteristics. A wide range of treatment and management strategies are now available.

Typical behavioural features include ADHD, OCD, autism-spectrum and anxiety disorders, with aggressive tendencies in some pubertal and adult males. Hyperarousal is a feature of FXS, often triggered by prominent sensory defensiveness, and self-modulation is often difficult for the individual. Social anxiety and avoidant personality disorders are common in females with selective mutism in severe cases. A subgroup of premutation carriers may be more mildly affected with the same emotional and executive function difficulties. Fragile X Tremor Ataxia Syndrome (FXTAS) has recently been described to affect predominantly older male premutation carriers.

Conditions treated in FXS include ADHD, mood disorders, anxiety, OCD, aggression and self-injury, epilepsy and sleep disorders. In most cases, the appropriate use of medications for treatment of these conditions will lead to a marked improvement in behaviour. It is emphasised that medications are used to treat a disorder, rather than a behaviour per se. An understanding of the antecedent triggers that may stimulate inappropriate behaviour in each individual is necessary in order to facilitate appropriate management strategies. A wide discrepancy between verbal

and functional skills is typical, this often leading to inappropriate demands or expectations of the individual, with consequent behavioural problems. The implementation of both behaviour management strategies as well as psychopharmacological agents are recommended, both approaches being synergistic when used in combination.

Life threatening physical health problems masquerading as behavioural/mental health disorders: two case studies.

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The interface between physical and mental health is regularly highlighted in a joint clinic set up with a developmental paediatrician, physician and psychiatrist. In the 5 years of operation of this monthly clinic, around 250 patients have been assessed and followed regularly. Most have complex mental health disorders, often accompanied by high medical needs and major social and care challenges. Two cases highlight the complex interplay and difficulty in diagnosis and access to appropriate services.

The first case involves a 20-year old lady, whose primary diagnosis is down syndrome. She presented with a range of physical health problems over a 12-month period, followed by an acute psychotic episode requiring prolonged hospitalisation.

The second case is that of a 25-year old male with a rare familial genetic disorder. He has a significant long-term mental health illness and recently, re-presented with severe challenging behaviour, resulting in presentation to a hospital emergency department. After discharge on antipsychotic medication, he re-presented to a different hospital with upper airway obstruction, necessitating admission to the intensive care unit.

Suitable staff training and access to appropriate medical services remain a challenge for people with an intellectual disability and co-existing physical and mental health problems.

Day three: Session one – Management Psychiatric Disorders and Autism

Experience of a randomised control trial of risperidone and haloperidol in adults with intellectual disability.

Dr David Harley

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There are potential benefits and risks in the use of antipsychotic drugs in adults with an intellectual disability. Communication difficulties make diagnosis difficult and antipsychotic drugs are often used to manage challenging behaviour in the absence of a diagnostic hypothesis or plan for monitoring response. Overuse or poorly considered prescribing of these drugs can lead to harm.

There is currently a dearth of evidence for the use of antipsychotic medications for the management of challenging behaviour in adults with an intellectual disability. I will discuss a randomised controlled trial of risperidone, haloperidol and placebo for challenging behaviour in adults with an intellectual disability – the Australian arm of the UK study Neuroleptics in Adults with Aggressive Challenging Behaviour and Intellectual Disability (NACHBID). Recruitment is currently underway and I will discuss the recruitment process and the difficulties involved.

Should form follow function? What role do psychiatrists have in the care of offenders with intellectual disabilities?

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This paper explores the models of care being considered in the formation of a new National Secure Forensic Intellectual Disability Hospital in New Zealand. The new service has been commissioned following the introduction of legislation for the alternative placement of offenders with intellectual disabilities. New Zealand in common with many countries recognises that prison may not be the appropriate or most effective disposal for offenders with intellectual disabilities. Unlike many other legislatures New Zealand specifically excludes people with intellectual disabilities from Mental Health Legislation. Arguably the new Act will pass a veneer of socially acceptable standards to hide preventative detention and the longer term denial of freedoms to a group of people that society finds alarming and struggles to manage successfully.

The New Zealand Legislation chooses a hybrid course between social care and medical models that lays a direct challenge to health services to justify what we can and perhaps what we should provide. In the development of models for the new hospital unit many challenging issues have arisen in considering how the underlying philosophy of care dictates the structure which affects the services provided and ultimately alters the outcomes sought and achieved.

Explicit discussion of the process and proposed solutions will be presented and the audience invited to challenge their own underlying models and presumptions and to contribute ideas that might be incorporated into the living experiment being enacted in New Zealand.

The effectiveness of a parent education and skills program for rural parents with a pre-school child with autism.

Dr Avril Brereton, Professor Bruce Tonge, Kerrie Bull and Melissa Kiomall

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The efficacy of psychological treatments is established by randomized controlled trials usually using research team therapists in clinical academic settings. Therefore the effectiveness of these

interventions in 'real-life' community settings often remains in doubt. We have demonstrated the efficacy of a 20 week Parent Education and Skills Program for parents of pre-school children with autism in producing a significant and sustained improvement in parental mental health and adjustment.

This paper reports the use of this program by early childhood professionals working with parents with a young child with autism who live in a rural area. Even though these children receive 70 per cent less early intervention services than metropolitan children the parent education program produced equivalent improvements in parental mental health compared to the original empirical evaluation of the program. This validation study confirms that a parent education program for parents of children with autism can be effectively delivered by trained early childhood professionals working with relatively isolated rural families.

Day three: Session one – Challenging Behaviours

Profiles of adults with intellectual disability and behaviour problems.

Dr Teresa Iacono, Stella Koritsas and Associate Professor Robert Davis

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Dr David Hamilton

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Most research into factors that may influence problem behaviours of people with intellectual disability (ID) focus on either mental or physical health issues, or take a behavioural analysis approach. There have been few attempts, however, to examine multiple factors that may influence problem behaviours. The aim of this study was to investigate associations between problem behaviours of people with ID and their environments, physical and mental health, adaptive functioning, communication skills and life events.

Eight adults with ID (aged 19-50 years, M = 35) and their support workers were participants. A series of assessments were administered that involved proxy reports by direct support workers and/or observation of participants with ID to provide profiles of participants and their problem behaviours. The results indicated that most problem behaviours were in the form of physical aggression ($n = 6$), verbal aggression ($n = 6$), and self injury ($n = 3$). Using Spearman correlations and $p < .05$, the overall severity score for problem behaviours correlated negatively with level of adaptive functioning ($\rho = -.88$), self absorption ($\rho = .70$) (on a psychopathology screening tool), and level of communication ($\rho = -.82$). Significant correlations between our other measures revealed a number of associations between mental health, behaviour functions, and level of communication.

These results along with more detailed profiles of participants point to clusters of factors that may be associated with particular types of problem behaviours and their functions. Such clusters require more detailed investigation with larger sample groups.

Gaining perspective in the causality of self-injurious behaviour (SIB) in people with intellectual disability.

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Background: Self-injurious behaviour (SIB) in people with intellectual and developmental disability are common and have a wide range of presentations that result in life style restrictions and high service costs. Past research showed associations with the aetiology of intellectual disability, autistic spectrum disorders, communication skills, the living environment and degree of intellectual disability. The impact of concurrent psychiatric disorders has remained questionable. Few studies have compared the relative impact of these factors or looked at SIB over time.

Aim: To investigate SIB over time and identify predictors and their relative impact.

Method: An epidemiologically representative cohort of 591 children and adolescents with intellectual disability, 59 people with Fragile X syndrome, 58 with Prader Willi syndrome, 61 with William's syndrome and 106 with Autism reported 3 times on a range of SIB topographies over an 8 year period.

Results: SIB was shown to persist over time. The importance of biological and psychiatric determinants for severity and characteristics of SIB was demonstrated. Major life events had little significant impact. Communication impairment, expressive or receptive, and some types of communication devices greatly increased the risk of SIB. Psychiatric 'caseness', high scores for "Social Relating" and "Self Absorbed" factors as determined by the Developmental Behaviour Checklist (DBC), the degree of intellectual disability and aetiology significantly and persistently impacted on the presence, severity and type of SIB.

Conclusion: Communication difficulties and the presence of psychiatric problems as detailed in the DBC are amongst the strongest predictors of these behaviours.

When nothing you do seems to work: assisting to turn around worker's perceptions of challenging behaviour in intellectual disability clients.

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One of the primary aims of this paper involves changing our understanding about challenging behaviour. The emergence of challenging behaviour in people with intellectual disabilities promotes the development of behavioural techniques aimed primarily at reducing the behaviour through contingency management, managing environmental factors, positive strategies and diversionary techniques. However, in the more resistant situations of challenging behaviour these approaches can become less effective in a context where carers become exhausted and the confidence of those supporting the person with the intellectual disability is eroded by the high levels of resistance and low level of impact on the behaviour, anxiety about risk of injury, and emerging resentment toward the client. This paper presents a process that is

still in the very early stages of its development. It involves a review of the nature of the challenging behaviour to i) incorporate the concept of emotional regulation in the client ii) retargeting the carers in supporting people with intellectual disability with information contained in the many hundreds of brief positive interactions that occur.

We aim to use this understanding to develop a relationship-based model that strives to work collaboratively from where the person with the disability is at. Our work involves video analysis, editing and reframing. Hence, this presentation will discuss a process use of video analysis and presentation to review the strengths of our clients and enhance our capacity to reframe challenging behavior.

Day three: Second Keynote Address

Intellectual disability, ageing and health outcomes: mind the gap.

Professor Philip W Davidson

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Population demographics of adults with I/DD appear to be following a trend toward increasing survivorship with increasing age. In 1970, only about 11 per cent of people with I/DD in the US were over age 55. By the year 2040, that percentage is expected to double. This trend is similar to what has been reported from the general population, and is generally due to improved health care, better nutrition, and other health risk-reducing factors that in turn lead to greater longevity. As more persons with I/DD survive into older age, changes will be required in the health care delivery system, now not prepared to anticipate the needs of such citizens. Unlike their non-disabled counterparts, survival into old age for persons with I/DD is relatively recent phenomenon, mainly due to such factors as the de-institutionalization movement in the latter part of the 20th century, increased emphasis on normalized family supports, community-based services, and health care derived from generic community resources.

There is a very limited literature on healthy aging among persons with I/DD. The trajectories of normal and non-normal aging in this population are generally not well understood. Hence, it is difficult for health policy planners to anticipate the special needs of the population that might result from older age morbidity, loss of functional ability, or the appearance of unexpected secondary conditions.

Since the mid-1990s, researchers have observed that that key questions remain unanswered and that we are therefore unprepared to assure the oncoming generation of people with I/DD who will survive into old age of a chance for healthy aging in place. More recently several international meetings have focused on this issue. The main recommendations emanating from these meetings emphasized the need for more research to clarify health outcomes and risk factors for preventable morbidity among adults with I/DD as they age. There are at least several general aims that such research should inform: First, to clarify the health status of a representative cohort of adults with I/DD. Second, to catalogue the impact of age-related health compromises affecting both people with I/DD and their caregivers and determine the synergistic effects on each group. Third, to identify health outcomes among adults

with special needs, including down syndrome, cerebral palsy, Autism, severe behavioral and psychiatric disorders. And fourth, to design and test best practices for primary and tertiary health care and organ-system specific interventions.

Day three: Session two – Anxiety Disorders

The burden and cause of anxiety disorders in individuals with intellectual disability.

Professor Bruce Tonge, Stewart Einfeld, Kylie Gray, Caroline Mohr, John Taffe and Emma Lourey

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Anxiety is often an unrecognized and disabling condition further handicapping the lives of individuals with ID. Questionnaire and interview information from the past 14 years of the Australian Child to Adult longitudinal study of young people with ID was reviewed to determine the course of anxiety disorders. The population of males with an anxiety disorder remained relatively constant at 9-10 per cent from childhood to adulthood. Anxiety was more common in females and rose from 12-14 per cent in children to 20 per cent in young adult women.

Anxiety is even more prevalent in individuals with Autism and Williams Syndrome and significantly increases in young adults with Fragile X Syndrome.

Anxiety disorder in adults was independently associated with poor parental mental health, negative life events, limited social networks and opportunities and parental overprotection. The implications for prevention, early intervention and treatment will be discussed.

Assessing anxiety in adults with intellectual disability.

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Australian and international survey data indicate that amongst adults in the general community, anxiety disorders are the most frequently diagnosed mental disorders. They also commonly occur in conjunction with depression and both conditions are associated with significant disabling effects as well as high social and economic costs. Factors such as temperament, parenting, modelling and exposure to loss and trauma can be implicated in the development of anxiety disorders in the general population and most adults will be able to report their symptoms to a clinician at the primary care or specialist mental health care level. Little is known about how anxiety disorders develop in adults with intellectual disability and assessment can be challenging as most people with intellectual disability have some level of communication difficulty that impairs their reporting on subjective experience.

A variety of assessment methods have been used with this population, in direct care as well as primary and secondary mental health care settings. Many of these are checklists or semi-structured schedules that indicate problem level anxiety. Others provide a diagnostic indication of possible case level disorder as defined by

ICD or DSM classification frameworks. Some rely on respondent (self rating) reporting whilst others source data from informant carers. This paper reviews many of the commonly available assessment methods and considers their suitability for direct care, primary health care and specialist mental health care settings. The use of suitable methods to accurately assess anxiety in adults with ID may help to guide referrals within a complex service system and obtain suitable treatment interventions in these settings.

Interventions for anxiety in adults with intellectual disability.

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Significant advances have been made in the evidence base for psychological treatments of anxiety in adults within the general population. The literature on psychological interventions for anxiety in adults with intellectual disability (ID) is still quite limited though. It remains difficult to determine whether treatments for this group should be unique or should replicate those which have proved effective for the general population. Evidence is emerging that modified cognitive behavioural interventions could be helpful and there is a history in the ID field of treatments based on applied behaviour analysis. Some intervention studies focus on problem level anxiety whilst others target case level anxiety disorders. Variation in classification systems and in research methodologies can also hinder comparisons across studies.

The relevance of interventions for the service system in which they will be applied is also important. The role of the primary health sector in mental health care has expanded in the past few years and the specialist mental health services have further defined their roles. Traditionally, adults with ID have had difficulty gaining access to the mental health system and the importance of direct care sector (carers and support staff) has been underestimated. This paper reviews the literature on effective interventions for problem level anxiety and case level disorder in adults with ID. Features of effective interventions will be presented and the importance of co-ordination across the direct care, primary health care and specialist mental health care systems is emphasised.

Day three: Session two – Dual Disabilities Doubled

Improving addictions services for clients with developmental disability.

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This oral presentation is appropriate for Day 3 of the conference, and covers service delivery, care at the interface between services and health outcomes.

This project was set up in the first instance to assess the prevalence, scale and challenge of drug and alcohol issues for people with learning disabilities in the London Borough of Wandsworth.

A literature search made it evident that there was little academic study of this particular dual diagnosis.

A special interest group was set up, drawn from professional health and social care workers in the fields of learning disabilities and substance misuse. The members of the group represented both governmental, National Health Service and voluntary service providers. A survey was commissioned, which found that there was a lack of knowledge on available services and referral protocols. There was a clear need for training for workers, and there was also concerns surrounding the issues of stigma, prejudice and exploitation.

A worker was appointed to develop services, and training set up. The training is aimed at gaps in the worker's knowledge. For example, Learning Disability staff are trained in addiction, and addictions staff in learning disability.

A 20 minute video has been produced, covering the dangers of drug and alcohol use, as part of a package of educational materials produced by the people with learning disabilities.

Links between services, and awareness of the issue, has been improved by work carried out by the Wandsworth Alcohol Forum and the Wandsworth Alcohol Services Access Facilitator. Whilst addictions services expect the client to have some motivation to change their behaviours, people with learning disabilities are often unable to recognise their abuse problems, may display behavioural problems and be unable to cope or benefit from cognitive based addiction programmes.

A life worth living – borderline personality disorder and intellectual disability: dialectic behaviour therapy.

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Dialectic Behaviour Therapy is a model of treatment well established and recognised for people diagnosed with borderline personality disorder. I have modified this treatment programme for people with an intellectual disability. The cases I have worked with have been highly successful.

In this presentation I explain the diagnosis of borderline personality disorder in people with an intellectual disability and the limitations of such. The question of 'maladaptive coping strategies' may be understood as a function of a 'maladaptive' environment, and the diagnosis of BPD needs to be made with caution. Dialectic behaviour therapy defines BPD as a pervasive dysfunction of the emotion regulation system, caused by a combination of temperament and an invalidating environment. I describe the treatment stages of DBT, and how these have been applied for a client with an intellectual disability. Components include commitment strategies (both for the client and the residential service), skills training and homework, chain analysis with the client about her own behaviour, and a behavioural management plan, again designed in cooperation with the client. I will discuss the wider implications of the use of this model for people with an intellectual disability.

Personality disorder in intellectual disability: characteristics and health outcomes.

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Very little research has been conducted on personality disorders within the population of people with intellectual disability despite suggestions that this population have a heightened risk for these disorders. Furthermore people with a diagnosis of personality disorder are reported to present a significant challenge to services. The Victorian Dual Disability Service is a specialist mental health service for people with intellectual disability in Victoria and this study aims to describe the clinical and demographic characteristics of a non random sample of 49 patients with a diagnosis of personality disorder who were referred by public mental health services. It also compares health outcomes using the Health of the Nation Outcome Scales – Learning Disability (HoNOS-LD) and CGI to reflect the changes between assessment and three month follow up. The implications and difficulties that individuals with an intellectual disability and comorbid personality disorder present to service systems are discussed.

Day three: Session two – Autism

Screening for autism in young children with developmental delay.

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Despite the finding that parents of children with autism report noticing abnormalities and problems with their child's development at a very early age, research shows that diagnoses are often made at an age beyond that recommended for the commencement of early intervention. Research on the reliability of early diagnosis and the identification of early features has paved the way for the development of autism screening tools. Screening for at risk children has the potential to assist in lowering the age at which autism is diagnosed, and facilitate the earliest possible commencement of intervention and support.

The results of a study which assessed the efficacy of the Developmental Behaviour Checklist (DBC) as a screening tool for autism in children with developmental delay aged 18–48 months will be reported. Analyses aimed to identify those items of the DBC which best predicted the diagnosis of autism. Univariate logistic regressions were performed to establish which items of the DBC differentiated the autism and control groups. A confirmatory factor analysis was performed with the 30 items identified by the univariate logistic regressions. Factor loadings were then used to develop the DBC screening algorithm. Receiver Operating Characteristics (ROC) analysis was used to evaluate the overall performance of the DBC algorithm as a screening tool for autism. Using a cut point of 0.60 or greater, 17 DBC items were selected to create a DBC autism screening algorithm.

A ROC curve was generated for the 17-item DBC screening algorithm, generating an AUC of 0.871 (SE = 0.033). Data will be presented on the sensitivity and specificity of the proposed screening tool, along with the results of a community based field trial.

Stress, sleep, and mental health problems in people with autism spectrum disorder.

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People with autism spectrum disorders (ASD) have a life-long developmental disability characterised by significant problems in communication and social interaction, a restricted range of interests, and in many cases, stereotyped body movements. Most people with ASD also have an intellectual disability. It has long been thought that people with ASD experience high levels of stress. This may be because they do not have adequate skills needed to cope with environmental stressors. Most of the evidence on stress, however, is based on research with children. Furthermore, little is known about anxiety in adults with ASD. Most of the evidence to date is based on studies of children and adolescents or adults who also have severe intellectual disability. For evidence of anxiety experienced by higher functioning adults with ASD, we rely currently on autobiographical accounts.

In addition, children and adults with an ID and children with an ASD, commonly experience sleep disturbance, which is associated with indicators of psychopathology (in particular anxiety), challenging behaviours, and with medication use. There is a clear need to explore stress and sleep in adults with an ASD as indicators suggest that these problems are associated with negative sequelae including psychopathology and impaired daytime functioning. This is particularly concerning as this group of people are already psychologically and developmentally compromised.

This paper will review the current evidence on stress, anxiety, and sleep problems in people with an ASD, and will outline directions for future research.

The difficulties in differentiating autism from schizophrenia in adults with intellectual disability.

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Significant progress has been made in the diagnosis and management of less severe forms of autism spectrum disorder. Traditionally, the diagnosis of autism was given where criteria for the developmental disorder were clearly satisfied and the level of associated disability significant or severe. A group exists who exhibited fewer or less severe symptoms and were not judged as autistic but in whom current clinical practice would now allow a diagnosis within the milder range. Analysis of clinical activity data for the Victorian Dual Disability Service indicated that some members of this population were diagnosed with a psychotic illness

in their adolescence and treated in the adult public mental health services. The aim of the paper is to illustrate the difficulties in the differential diagnosis between autism and schizophrenia in adults by outlining some of the service system issues and comparing and contrasting the disorders on the following dimensions; the nature and classification of the disorders; the developmental history and clinical presentation; the history and mental state; the response to treatment; the course of the disorder.

On the basis of the discussion above an attempt is made to identify the similarities and distinguishing characteristics of the two disorders and to examine how these can be accounted for in the assessment process.

Day three: Session three – Aged Care Workshop

Part 1: Comprehensive geriatric assessment for evaluating functional decline in older adults with intellectual disabilities.

Professor Philip W Davidson PhD

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Functional decline in older persons with intellectual disabilities (ID) may result from a number of aging-related conditions. The link between dementia of the Alzheimer type and down syndrome has been widely publicized. Caregivers may overlook other conditions amenable to management or treatment, assuming the presence of non-reversible dementia even when the client does not have down syndrome. Most health care providers may not sort out the impact of undiagnosed or inadequately treated medical disorders, environmental barriers, and psychosocial factors pertaining to older age. Differential diagnosis requires examination of multiple factors in several sites, on several occasions, and this may have to occur with patient communication and compliance limited by ID. This workshop presents a model Comprehensive Geriatric Assessment (CGA) clinic designed exclusively for older individuals with ID, and describes findings from assessment of clients evaluated between 1995 and 2001. Further development of such model clinics may improve identification of aging-related potentially reversible causes of functional impairment in older adults with ID.

Part 2: Clinical assessment of Alzheimer's disease in people with down syndrome and treatment with cholinesterase inhibitors.

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The diagnosis of Alzheimer's disease (AD) in people with down syndrome (DS) is complicated by the presence of comorbid conditions and pre existing communication, cognitive and functional impairment. The early stages of AD in people with DS are characterized by personality and behaviour change and a variety of psychiatric symptoms. However diagnosis of Alzheimer's disease requires demonstration of progressive impairments in new learning, language ability and visual spatial skills and the development of dyspraxia and agnosia. There is a small body of evidence

suggesting that cholinesterase inhibitors may result in modest benefits for people with DS and AD however care must be taken given common cardiac anomalies, propensity for seizures and the difficulty in identifying gastrointestinal and other side effects. This part of the workshop presents practical clinical assessment of AD in people with DS and treatment with cholinesterase inhibitors.

Day three: Session three – Communication Workshop

Augmentative and alternative communication for people with complex communication needs.

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Many people with developmental disability, such as intellectual disability, cerebral palsy and autism, have complex communication needs. As a result of limited or no speech skills, they rely on formal and/or informal Augmentative and Alternative Communication (AAC) – for expressive and often also for receptive communication. AAC systems include the use of gestures, signs, communication boards and books, and electronic speech generating devices. In this workshop, we aim to (a) provide an overview of the application of AAC, (b) discuss collaboration with speech pathologists, (c) demonstrate various AAC strategies, (d) present case studies of individuals with developmental disability who rely on AAC, and (e) provide practical examples of the use of AAC in the community to enhance community inclusion. In addition, the use of AAC within clinical situations, such as a general practice consultation, will be discussed.

Day three: Session three – Diagnostic Criteria / Learning Disability Workshop

Assessment and classification of mental ill-health in adults with intellectual disabilities.

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This workshop will consider briefly the background to assessment and classification of mental ill-health in adults with intellectual disabilities, and will present some research data comparing the classificatory systems DSM-IV, DCR(ICD-10), and DC-LD with specialist intellectual disabilities psychiatric clinical diagnosis. The focus will be on application in clinical practice. A framework for assessment will be discussed, as will its purpose to inform the development of plans for interventions and supports.

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Products and resources

- **Internationalised Flexible Learning Distance Education subject on the Psychiatry of Intellectual Disability**
- **Personal Health Records**
- **Menstrual Management and Women with Intellectual Disability – Guide for GPs**
- **Options for Menstrual Management – Resources and Information for Staff and Carers of Women with an Intellectual Disability**
- **Epilepsy: The plain facts**
- **Pap test: The plain facts**
- **ASK – Assessment of Sexual Knowledge: A sexual knowledge assessment tool for people with an intellectual disability**
- **A Smoking Education program**
- **Hospital care for people with a disability: A quick reference guide**
- **Management Guidelines for People with Developmental and Intellectual Disability**
- **Healthcare Scenarios in Developmental Disability Medicine – CD**
- **Forever Baby – Jenny’s story – a mother’s diary**
- **Fact Sheets on:**
 - Angelman Syndrome
 - Autism Spectrum Disorder
 - Cerebral Palsy
 - Challenging Behaviour
 - down syndrome
 - Epilepsy
 - Fragile X Syndrome
 - Rett Syndrome
 - Noonan Syndrome
 - Prader Willi Syndrome
 - Tuberous Sclerosis
 - Sexuality
 - Health promotion



Better Health
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