

I ASSID Health-SIRG Newsletter

I ASSID* Special Interest Research Group
(SIRG) for Health Issues
January 2003

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* International Association for the Scientific Study of Intellectual Disability

Chairperson's Word

Health Disparity and the Health SIRG

This seems to be an important year for our SIRG. We have two clear targets this year. The first to have a successful Health SIRG meeting in New York and the second to formalise the contribution of the Health SIRG to the IASSID 2004 meeting in Montpellier, France. Both these issues were raised in the last newsletter but now time has passed and they have become very much a reality.

Things are already fairly advanced for the 2003 meeting. We are going to have the meeting in the USA hosted by David O'Hara at the West Chester Institute of Human Development in New York Medical College, Valhalla, New York. The meeting is titled: Reducing health disparities for persons with intellectual disabilities. Developing an agenda for change.

The meeting will be a workshop format with probably quite limited spaces and will address the disparity in the health status of people with an intellectual disability. The meeting is designed with the output in mind. We aim to produce a Health SIRG position statement on health disparity from the workshop. The dates have been fixed as August 25-27 2003. Further details will follow shortly.

The organising committee for the Montpellier have asked the individual SIRGs for a more active input into the program contents. The aim is for one-hour themed symposia. Probably 3 presentations with discussion. **We need to collate these by March if possible.** Therefore if you know that a collection of individuals will be attending Montpellier and have presentations that could be put into a one hour symposium please let me know so we can inform the scientific committee. (mp_kerr@yahoo.com).

Mike Kerr

Steering Committee Business

Minutes of Annual General Meeting IASSID Health SIRG, Glasgow 5.35 PM Wednesday September 11, 2002

1. Opening and welcome

Chairman Mike Kerr welcomed members to the meeting

2. Present

Heleen Evenhuis, Robyn Wallace, Bob Davis, Mike Kerr, Vee Prasher, Thomas Cheetham, David O'Hara, Helen Beange, Helen Maloney, Seeta Durvasula, Nick Lennox, Michael Drayton, Olive Webb, Monica Bjorkman, Henny Lantman, Lynette Lee

Apologies

Sally Anne Cooper

3. Minutes of the Annual General Meeting In Goteborg, Sweden Sept 2001.

Moved Helen Beange Seconded Vee Prasher and approved that we accept minutes of the annual general meeting in Goteborg, Sweden Sept 2001.

4. Chairperson's Report

Presented by Dr Mike Kerr (attached)

5. Membership and Newsletter

Vee Prasher: Present Membership is 52 on our list as members Matt Janicki has indicated that IASSID is insistent that SIRG complies with the rules of IASSID SIRGs in that all "members" are members of IASSID. There have been some issues in coordinating the lists with Matt. Vee will contact those members on his list to ensure that they are aware that they need to be members of IASSID Mike Kerr stated that the standard of the newsletter was again very high this year an that it played an important role in linking the membership. Robyn Wallace: Thanked those who had contributed and indicated that it helps her considerably if people submit articles and news to her in a timely manner.

6. Financial Report & Financial Plan

Vee Prasher reported that the Health SIRG had approximately \$US2500 which was up by approximately

\$US1000 more than this time last year. This money had been accumulated through membership fees and some money's surplus from the Gotenberg Roundtable. Outgoings at this stage were only from the cost of teleconferences for committee meetings and the 2002 Round table working party.

7. Business Arising

No items apart from the agenda

8. Update from IASSID

There was some discussion about an advocacy group submission about access to the forthcoming IASSID conference. This was triggered by a concern about the accessibility of some parts of the venue at Montpellier. The organisational committee has taken this on board and try to ensure that this is dealt with as best as possible. There was also a concern voiced by a small group of individuals about the "scientific use of people with disabilities.

IASSID has asked that each of the SIRG work towards the development of "Fact sheets" to be distributed amongst the general membership and the wider public on the issues of concern, recommendations etc of the health SIRGs

9. Report from representative of program committee IASSID congress 2004

Mike Kerr reported that Neil Ross and David Felce were keen that the Health SIRG develop themes and interest groups for presentation at IASSID with 1½ hour small symposiums. These would have responsibility for organising groups of speakers and hopefully overcome the disparity of some of the program in Seattle. This will need to be organised over the next year. The SIRG could use the newsletter and its e-mail lists to identify individuals and encourage this process.

10. Health SIRG roundtable New York State, September 20 - 22, 2003

The meeting was informed that after approval from the committee Mike Kerr, Bob Davis and David O'Hara had met to organise the 2003 Roundtable to be held within the USA. It was felt that this was timely given the recent release of the Surgeon General's Report on Intellectual Disability and

strategic in that the SIRG needed to better engage our American colleagues. David O'Hara was prepared to organise this for some time in September 2003 in Westchester. Unfortunately as there were a number of meetings around this time the date was an issue. There was some discussion on the theme and format for the conference. Mike felt that the meeting should develop discussion on identifying inequalities and ways of overcoming these. The Health SIRG had some credibility and returning to the Roundtable format would be an effective way of promoting the health agenda for people with developmental disability.

Moved Robyn Wallace that we hold a Roundtable at Westchester New York with the final date and venue to be organised by David O'Hara and the structure to be decided by the organising committee. Seconded Helen Beange and carried unanimously.

11. Other business

Mike Kerr reported that MAMH had concerns at the timing of meetings and conferences and asked that where possible we avoid clashes by keeping each other informed. There was recently a problem with the times of the European IASSID meeting in Dublin clashing with the MAMH meeting in Budapest. Resolved that where possible we would avoid this but that at times there were limitations in the times available making a clash inevitable.

12. Nomination and Election of steering committee for 2002-2003

The following members were nominated to the committee:

Vee Prasher, Mike Kerr, Helen Beange, Robyn Wallace, Henny Lantman, David O'Hara, Olive Webb, Markus Kaski, Bob Davis. As positions exceeded nominations the elected members have been appointed and after election within the committee the Committee for 2002 -2003 is as follows:

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Committee Members

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Markus Kaski markus.kaski@rinnekoti.fi (subject to confirmation)
Henny Lantman Henny.Lantman@HAG.UNI MAAS.NL

13. Meeting Closed at 7.00 PM

Next meeting to be advised in Westchester, New York State USA

BOB Davis

International Roundup News

- **2003 Health SIRG Meeting, New York, August**

The dates have been finalized- New York, August 25-27th – not September as initially thought. This is an important international meeting which provides a unique forum for health professionals to discuss physical health clinical and research issues of adults with intellectual disability at the expert, informed level. A position statement will be formulated on the topic of reducing health disparities for people with intellectual disability. The Health SIRG Annual General Meeting is traditionally held at this meeting too.

Topic: **Reducing health disparities for persons with intellectual disabilities. Developing an agenda for change.**

Date: August 25th-27th 2003

Place: West Chester Institute of Human Development in New York Medical College, Valhalla, New York

Convenor: David O'Hara DAVID_OHARA@NYMC.EDU

- **Ethics standards**

Keith Mcvilly, Australia, and Arthur Dalton, US, have recently distributed a draft document on ethical considerations for studies involving people with intellectual disability. This document will be particularly useful in settings where guidelines do not already exist, or at least, not in any sophisticated way. Moreover, they should also provide the basis for common ground when establishing international multi-centre trials involving people with intellectual disability.

If you have a particular interest in this area or are considering research, you may wish to be more informed; please contact Keith on kmcvilly@med.usyd.edu.au or Arthur on DaltonAJ@aol.com

Clinical Corner

- **"Dear Dr --please admit urgently"**

I was thinking about patients who needed immediate admission after I had seen them in Out Patient Clinics, and suddenly realized that although few in number they shared a common characteristic. This was the fact that they all lived alone, with drop-in staff supervision. I searched my memory again and came up with only one patient who was urgently admitted from a fully staffed house. The latter was a youth with Down syndrome, and a history of Hirschsprung's disease, who became very anaemic and was transfused.

Here are the cases, details altered to disguise identities.

1. **James M.** Man about fifty, mobile, healthy, no medication, moderate intellectual disability. He lived alone in a suburban house, attending a sheltered workshop by day, staffed by workshop staff residential visitors. In spite of a previous excellent attendance record, James stopped attending the workshop saying he was "too tired". The local GP was asked to visit. He knocked at the door, which opened after a long wait. My patient had crawled to the door from his bed. The

doctor examined James but could find nothing and informed the workshop that there was no physical reason for the absenteeism. A workshop manager who was both canny and observant brought him to my outpatient clinic saying she noticed that he “suddenly looked old”. He looked very sick, although afebrile, no obvious signs. He was admitted from A& E and proved to have septicaemia, a complication of an episode of osteomyelitis of the femur contracted as a young man. James recovered uneventfully.

2. **Ronald S.** Mild intellectual disability, 40. Discharged from large institution to live independently in community, drop in supervision by a non-profit agency. Ronald continued to work at the institution’s day centre after discharge, although this involved a journey across Sydney by bus and train. He was noticed to be losing weight, and neglecting to feed himself. He said eating “made him sick”. He often was late for work, or missed work. Eventually he stayed in bed all day and could not be persuaded to get up. His GP noticed pallor and began iron therapy. His carer expected him to return to the workshop but although improved, he stayed indoors. She asked me for an opinion. At our clinic I found him pale, thin, and mildly cyanotic, with tachycardia and a loud murmur, and sent him by ambulance for admission to the local teaching hospital. He had ulcerative oesophageal reflux disease, microcytic hypochromic anaemia,(haemoglobin 7), and early heart failure, and responded quickly to treatment.
3. **Graham G.** A young man with Down syndrome, living alone with drop-in support from mother and from an agency. There were many complaints about his non-compliance and lack of hygiene. Day care was available but rejected. He had episodes of diarrhoea and faecal incontinence. Efforts made to obtain staffed residential care by his worried carer were without avail as he had been “proven to be capable of independent living”. The carer asked me to see Graham urgently when his gait changed to a stiff painful hobble. On

examination there was extensive ulceration and excoriation of the perianal area, which was unclean because it hurt him too much to wash. He was admitted to his local hospital for dressings and antibiotics. After discharge the local authorities found a place for him in a staffed group home.

I have been a clinician practising in intellectual disability medicine for many years and have probably seen at least a thousand patients, many of whom had severe undiagnosed disorders, but who did not need urgent admission. Admittedly this is not an epidemiological sample, but it is an extensive clinic series. I estimate that I see ten times as many people living in staffed group homes as those who have drop-in support. Perhaps the relative risk of admission to hospital is raised in those who have significant intellectual impairment and live independently.

And another thing-----does anyone know any work describing the morbidity rates of adults with ID? Eg morbidity rates of notifiable diseases, GP consultations, sickness absence rates, hospital admissions, length of stay. It would be useful to compare these rates with those of the general population, and may also help to monitor our progress. Are we making a difference to the health of our patients?

Helen Beange

- **Clue to a cause of intellectual disability**

Many parents of adults with ID harbour personal guilt or anger at doctors for many years over the resulting intellectual disability in their adult children. Uncovering the cause of the ID often releases them from such feelings and creates feeling that "it all makes sense now", "it wasn't our fault afterall". There may be genetic implications. For the physician, this discovery too impacts on clinical practice where they now become vigilant for possible syndrome specific physical health conditions. In clinical practice for my adult patients with ID, I always review the cause of the ID. Sometimes the associated

history of physical health conditions can lead to the diagnosis, as the following case demonstrates.

A 31-year-old woman was referred for evaluation of long standing maladaptive behaviours and a physical health check. Her parents were deceased, her older brother was in regular contact and she lived in a group home. She had been admitted to multiple hospitals and institutions over the years since her parents died, and was now under the regular care of GP and psychiatrist. The cause of her intellectual disability was unknown. She had one eye removed because of an "eye cancer" during infancy. Family history of cervical and breast cancer. On examination, she appeared shy, displayed some ritualistic behaviours but was compliant with examination. She had a prosthetic left eye and dysmorphic facial features: joined single eyebrow, microcephaly, low set ears; limbs, cardiac, respiratory, gastrointestinal normal. Chromosomal analysis showed deletion of chromosome 13 involving the 14q region- likely the cause of her intellectual disability and retinoblastoma. She was also found to have hypercalcaemia (due to primary hyperparathyroidism), not reportedly part of this syndrome. The knowledge of the ID etiology made a tremendous positive difference to her brother and team of carers. The carers embarked on a behaviour management plan for her behaviour, which is now improving and antipsychotics reducing.

The case demonstrates:

- Adults with ID could have etiology of ID reviewed even if they have been "in the ID services for years"; new technology available since last review in childhood; may have never been investigated;
- Use phenotypic clues - if history of retinoblastoma think chromosome 13 and ask for this analysis;
- Not all patients with chromosome 13 deletions have a history of retinoblastoma- only those deletions affecting the 14q region seem to have this risk;
- Other chr 13 deletion syndrome specific health implications - risk of tumour recurrence, possible

increased risk for other tumours; other systems may be involved including cardiac problems, cryptorchidism, renal anomaly, other eye abnormalities, Hirshsprung disease;

- But don't forget the patient may also have other conditions unrelated to the syndrome;
- For Individuals with ID, their Family, Carers and Health professionals knowing the cause of the disability may have a positive impact- global understanding, relief, genetic, health;
- Advise to request permission to check for causes first.

Robyn Wallace

Research Corner

- **European initiative on health indicators-** POMONA project: Study on Health Indicators for People with Intellectual Disability.

Patricia Walsh (UCD Dublin), Mike Kerr (Cardiff) and Henny Lantman (Maastricht) are the steering committee of the Pomona project.

Aim of this project is to identify a set of health indicators that reflect important areas in achieving greater quality of life and equal opportunities for people with Intellectual Disabilities (ID) throughout the EU member states.

Paradigms for appropriate health care in countries vary widely at this moment, so it is important that we all adopt the same paradigm in looking at these issues. There is no consensus on what appropriate health care should include, and we will explore disparities in health status throughout the countries. Choice is often used as an argument to condone poor health status and practices. Unfortunately, people with ID lack appropriate and understandable information so as to make healthful choices.

We will base our work on an earlier EU report in which health indicators were identified for the general population (1). We will review literature and consult with partners from 13 EU countries (2) to make sure that we include the most urgent issues related to health of people with ID in their countries and that results will be disseminated. Partners will be invited to consult with local experts and relevant organizations within their countries so as to reflect national priorities and evidence-based practice. We intend to ensure that the findings will help to shape policy so that it contributes to a better quality of life for people with ID.

The first meeting with representatives from 13 countries will take place from 6-9 February in Montpellier, France. In workshops we hope to set a framework for our final results. The project will conclude with a final report on applicable health indicators and priorities for health policy in the participating countries in the Summer of 2004.

(1) The ECHI-report: Design for a set of European Community Health Indicators. Final Report by the ECHI project EU Luxemburg, 2001.

(2)The *Pomona* partners are: Charles Aussilloux (FR); Monica Bjorkman, (SWE); Serafino Buono(IT); Raymond Ceccotto (LUX); Meindert Haveman (GER); Frank Ulmer Jorgensen (DK); Mike Kerr (UK); Tuomo Maatta (FIN); Jan Meireleire (BE); Luis Salvador (SP); HMJ van Schrojenstein Lantman de Valk (NL); P.N. Walsh (IRL); and Germain Weber (AUS).

Henny Lantman

- Mainstream medical journals include intellectual disability health, ethical and research issues

The New England Journal of Medicine:

- M.R. Seashore. Perspective: Tetrahydrobiopterin and Dietary Restriction in Mild Phenylketonuria, December 26, 2002.

- M. Shevall. Hallevorden and History, January 2, 2003.
- G. Annas. Moral Progress, Mental Retardation, and the Death Penalty, November 28, 2002.

The British Medical Journal:

- D. Singh. Learning disability task force criticises draft mental health bill, January 25, 2003.

Meetings and Conferences

- August 25th-27th 2003 Health SIRG, New York

Place: West Chester Institute of Human Development in New York Medical College, Valhalla, New York

Convenor: David O'Hara DAVID_OHARA@NYMC.EDU

- 2004 I ASSI D Montpellier, France

see www.IASSID.org/

- 2003 June 26th- 28th Centre for Developmental Disability Studies, Sydney, Australia

see http://www.cdds.med.usyd.edu.au/html/about_us.html

- 2003 ASSI D, Brisbane, Australia

see www.ASSID.com.au/

The newsletter is freely available for people to post notices of their meetings in the area of healthcare for adults with intellectual disabilities. Please send your notices to the editor, R.Wallace@sph.uq.edu.au

Free Notice board

Thank you to the contributors to this newsletter!

Please send your notices, comments, cases, research snippets, and clinical initiatives to Robyn Wallace,

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- To become a Health SI RG member

To join a SI RG, you must also be a member of I ASSI D. To join a SI RG these are the steps:

1) complete the member information form (GO TO: <http://www.iassid.org/form.htm>),

(2) complete the membership level and SI RG payment information, and then

(3) complete the credit card payment information (GO TO: <http://www.iassid.org/marketplace/payment-page.htm>). Please

be sure to complete the payment page, as IASSID has received some membership forms without accompanying payments.

You can also pay for two years -- saving some dollars on a multi-year membership. To pay for two years, please be sure to indicate "2" in the quantity inquiry when you paid for a SIRG. To pay, go to www.iassid.org. You can also renew via fax or post -- IASSID's fax number is 1 518 877 3357 and the IASSID/US address is on IASSID, 31 Nottingham Way South, Clifton Park, New York, 12065-1713 USA.