



International Association for the Scientific Study of
Intellectual and Developmental Disabilities
Parenting with Intellectual Disabilities
Special Interest Research Group Newsletter

Dear SIRG members,

The IASSIDD 15th World Congress held in Melbourne, Australia, was another clear success! As always, our SIRG was well represented by 26 presentations from 8 different countries (Australia, Poland, United States, Canada, Sweden, England, Czech Republic, The Netherlands), 1 Master Lecture and 1 Accessible Lecture. We even got the chance to welcome new researchers in our field of study!

Our success was not only showcased by the number of presentations and presenters but also by our dynamism in organising ourselves and responding to priorities set four years ago. As you may recall, in 2012, at the 14th World Congress, our SIRG had established priorities that answered to the need for research that included fathers with ID, parents' voices, children of parents with ID, prenatal and pregnancy outcomes, large set statistics on prevalence and health. We were so amazed by how our SIRG took on this challenge! Look inside this issue for synopsis on the topics presented.

With all of those wonderful presentations, we suggest you look forward to our double-special issue in JARID that should be officially published in 2017. In the mean time, please look at accepted [articles online](#)!

Finally, we are now in the process of identifying further challenges and directions for research. The new SIRG executive will be presenting their objectives for the next three years and submitting those to you in the next few months.

With that said, we now have to praise our previous executive for providing such great leadership and clear direction that led this SIRG to be well represented in, not only, ALL IASSIDD Conferences and World Congress, but also many conferences by other disabilities Associations ([NNDR](#), [TASP](#)). Our past executive was also very efficacious in identifying gaps in knowledge and ensuring that SIRG members target those gaps in current research! Congratulations for a job well done and thank you!

Marjorie Aunos, Ph.D.

And

David McConnell, Ph.D.



2016



Inside this issue:

SIRG Topics	2
Upcoming Events	2
Hot off the Press	3
SIRG Executive	5
New Researcher Spotlight	5





Upcoming Events



The IASSIDD World Congress will now come every THREE years! The next meetings are:

- Asia-South Pacific Conference 2017 in Bangkok, Thailand
- Europe Conference 2018 in Athens, Greece
- 16th World Congress 2018 Glasgow, Scotland

TASP Bi-Annual Conference

Turning the Tide: Improving Policies and Practices Related to Parents with Cognitive Limitations

- September 25, 26, 27 2017
Minneapolis, MN.

NNDR 14th Research Conference

Nordic Network on Disability Research

- May 3-5 2017
Orebro, Sweden

IASSIDD 15th World Congress: SIRG Topics

Papers presented at the 15th World Congress addressed many of the priorities for research identified by the IASSIDD Parenting SIRG at the 14th World Congress. The following is a synopsis on the topics presented.

- One session was dedicated to hearing children's experiences of growing up with parents with ID. This session included three presentations from three different countries (Poland, United States and Australia) looking at general service support needs (Susan Collings) and voices of adult children (Agnieszka Wolowicz-Ruszkowska; Tammy Bachrach).
- Elements of large population-based datasets were analysed and elements on the health and behavioral and cognitive outcomes of young children of parents with ID (Robyn Powell) and the health of mothers (Monika Mitra) were presented, as well as prevalence estimates (Catherine Wade) and pregnancy outcomes for mothers with ID (Willi Horner-Johnson).
- Large datasets were also used to look at the social emotional well-being of children (Gabe Hindmarsh) and child welfare process and child outcomes (David McConnell).
- Two presentations focused on fathers with ID (Jon Symonds, Ashley Odgers). Not only were they informational but they were inspirational!
- As always, many presentations used clinical research samples to look at support for workers (Mikaela Starke), impact and used of clinical interventions for mothers with ID (Jana Bernoldova, Marja Hodes, Ann Fuge Schormans), choices made by mothers with ID (Amanda Guay, Margaret Spencer, Susan Arthur, Jos de Kimpe) and services processes and elements of collaboration (Marjorie Aunos).
- Two presentations focused on more theoretical framework for understanding the lived-experiences of parents with ID and their children (Sabina Kef, Lindsay Hahn) and Llewellyn represented 'us' in a more general stream on the importance of data linkage. Finally, we had our first 'Master's Lecture' presented by Laliberte!

Don't forget: Renew your IASSIDD membership

Take advantage of this opportunity for international and multidisciplinary networking; sharing information, developing initiatives, finding new colleagues and becoming visible to newcomers in the field.

To maintain your connection to this worldwide network of researchers and practitioners dedicated to understanding and enhancing the lives of parents with intellectual and developmental disabilities and their children, remember to renew your IASSIDD membership, and select the Parenting SIRG option.

Click [here](#) to renew your IASSIDD membership now

Hot off the Press

As our field expands new research on parents and parenting with intellectual disabilities is booming. We have selected three of the most recent publications to share with our SIRG members.

Ameliorating Psychosocial Risk Among Mothers with Intellectual Impairment

The purpose of this study was to pilot a flexible, group-based program designed to strengthen the social connections and enhance the psychological well-being of mothers with intellectual impairment. A multi-site, mixed-method, pretest-posttest design was employed. To obtain rich process and outcome data, the evaluation incorporated measures of psychosocial well-being, goal achievement scaling, and interviews with group facilitators and participants. A total of 18 mothers completed the program. Participation was associated with a meaningful reduction in psychological distress with effect sizes ranging from .57

for depression to .71 for anxiety. Participating in the group program gave the mothers something to look forward to each week, opportunities to learn from and support others, and the feeling of “being a part of society”. Further research is needed to determine whether these promising results can be replicated, and to evaluate the long-term impact of the program on mothers and their children.

McConnell, D., Feldman, M., Aunos, M., Pacheco, L., Savage, A., Hahn, L., Dubé, C., Chenier, S. & Park, E. (2015). [Ameliorating psychosocial risk among mothers with intellectual impairment](#). *Community Mental Health Journal*. DOI: 10.1007/s10597-015-9979-9

Midwives' comprehension of care for women with intellectual disability during pregnancy and childbirth: An open-ended questionnaire study in Sweden

Background: Few studies have investigated midwifery care for women with intellectual disability (ID).

Aim: To gain a deeper understanding of midwives' comprehension of care for women with ID during pregnancy and childbirth.

Methods: A cross-sectional study among 375 midwives at antenatal clinics and delivery wards in Sweden. Findings 2476 quotations were sorted into six categories: information; communication and

approach; the role of the midwife; preparing for and performing interventions and examinations; methods and assessments; and organisation of care. The midwives affirmed that individual, clear and repeated information together with practical and emotional support was important for women with ID. The midwives planned the care as to strengthen the capacity of the women, open doors for the unborn child and reinforce the process of becoming a mother. Extra time could be needed. They tried to minimise interventions. The mid-



“Participating in the group program gave the mothers something to look forward to each week, opportunities to learn from and support others, and the feeling of ‘being a part of society’”





Did you know?

- ONLY the first choice of SIRG gets financed by IASSIDD.
- To be an Official SIRG, we need 30 official members who selected our SIRG as their first choice – we currently have 27 ‘official’ members that follow this rule.

This means... we NEED to work on our membership!

Click [here](#) to renew your IASSIDD membership now



“a significant proportion of the poorer health of people with IDs may be attributable to their poorer living conditions rather than biological factors associated with ID per se”

wives felt a dual responsibility, to support the mother–child contact but also to assess and identify any deficits in the caring capacity of the mother and to involve other professionals if needed.

Conclusions: The midwives described specially adapted organisation of care, models of information, practical education and emotional support to facilitate the transition to motherhood for women with ID. They have a dual role and responsibility

in supporting the woman, while making sure the child is properly cared for.

Healthcare services should offer a safe and trusted environment to enable such midwifery care. When foster care is planned, the society should inform and co-operate with midwives in the care of these women.

Höglund, B., & Larsson, M. (2015). [Midwives’ comprehension of care for women with intellectual disability during pregnancy and childbirth: An open-ended questionnaire study in Sweden](#). *Women and Birth*, 28(3), e57-e62.

The health of parents with and without intellectual impairment in the UK

Background: Little is known about the health and well-being of the ‘hidden majority’ of parents with mild intellectual disability (ID), who are less likely to be in contact with disability services.

Method: We sought to add to knowledge in this area by examining the health and living conditions of parents with and without intellectual impairment in a large contemporary nationally representative sample of UK parents aged between 16 and 49 years old (n = 14 371).

Results: Our results indicated that, as expected, parents with intellectual impairment were at significantly greater risk than other parents of having poorer self-reported general, mental and physical health. They were also at significantly greater risk of experiencing higher rates of household socio-economic disadvantage and environmental adversities and lower rates of neighbourhood social capital and intergenerational support. Adjusting risk estimates to take account of between group differences in household socio-economic disadvantage eliminated statistically significant differences in

health status between parents with and without intellectual impairment on all but one indicator (obesity). Further adjusting risk estimates to take account of between group differences in neighbourhood adversity, neighbourhood social capital and intergenerational support had minimal impact on the results.

Conclusions: That controlling for between-group differences in exposure to socio-economic disadvantage largely eliminated evidence of poorer health among parents with intellectual impairment is consistent with the view that a significant proportion of the poorer health of people with IDs may be attributable to their poorer living conditions rather than biological factors associated with ID per se.

Emerson, E., Llewellyn, G., Hatton, C., Hindmarsh, G., Robertson, J., Man, W. Y. N., & Baines, S. (2015). [The health of parents with and without intellectual impairment in the UK](#). *Journal of Intellectual Disability Research*, 59(12), 1142-1154.

A New SIRG Executive Has Been Elected!

As of this World Congress, the following SIRG members constitute our new executive: Traci Laliberte, Hannah Bjorg Sigurjonsdottir, Margaret Spencer, Mikaela Starke, Susan Collings, David McConnell and our new chair : Marjorie Aunos. We all look forward to hearing of your proposal on what our SIRG objectives should be!

In the mean time, we all strongly recommend that you [renew your membership](#) AND that you select Parenting SIRG as your FIRST choice of SIRG. We also ask you that you inform you research collaborators of our SIRG and that you showcase our strength – maybe they would like to join our much dedicated and motivated SIRG!

New Researcher Spotlight

The IASSIDD Special Interest Research Group on Parenting with Intellectual Disabilities grows every year with promising new students and researchers from all over the world. Here we feature one of the many talented new additions to the Parenting SIRG.



Robyn M. Powell, JD, is a 2nd year PhD student at The Heller School for Social Policy and Management at Brandeis University as well as a Lurie Institute Doctoral Fellow under the supervision of Dr. Susan L. Parish. Most recently, Ms. Powell served as an Attorney Advisor at the National Council on Disability (NCD), an independent federal agency that advises the President and Congress on matters concerning people with disabilities.

Ms. Powell is principal author of NCD's [Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children](#). As a disabled woman, her research

interests include disability law and policy, particularly the needs, experiences, and rights of parents with disabilities and their children. Ms. Powell is currently conducting research on the wellbeing of parents with intellectual disabilities and their families. Ms. Powell is new to IASSIDD, having become a member in 2015, and was pleased to have presented her research at the 2016 World Congress.

Contact Robyn M. Powell at rpowell@brandeis.edu



**International Association for
the Scientific Study of Intellectual
and Developmental Disabilities**



**International Association for the Scientific Study
of Intellectual and Developmental Disabilities**