IASSIDD

SIRG QOL NEWSLETTER

JUNE 2024

IN THIS EDITION

VOICES LOST IN CRISIS:

PERSONS WITH IDD SHARE THIER EXPERIENCES OF COVID-19

INSIDE:

- HIGHLIGHTS
- SUGGESTED READINGS
- ACTIVITIES AT A GLANCE
- THROWBACK TO 2023
- KEEP AN EYE OUT: UPCOMING A ND ONGOING RESEARCH IN QOL

HIGHLIGHTS

Life as we know it has changed. The pandemic disrupted core elements of social inclusion, such as spending time in valued actiities, having meaningful relationships and feeling included (Hall, 2010). For an already excluded group, these experiences were further exacerbated for adults with developmental disabilities.

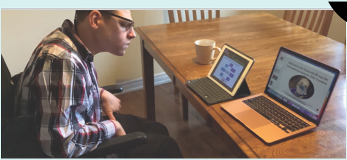
WORLD BECOMING (EVEN) SMALLER

"We go for a walk every darn day, probably twice a day when it is not freezing cold out […] This is kind of the path we have been taking for the last, I don't know, 360 days […] it's like groundhog day"

Interview

This participatory action research project utilized a Photovoice Methodology to capture the lives of 13 adults with IDD in Ontario during the COVID-19 crisis. This research aimed to identify concerns related to social isolation,mental health and overall quality of life.

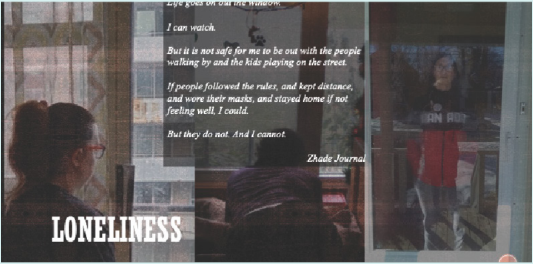
HIGHLIGHTS



To prepare for the project, we provided behavioural skills training remotely to teach participants how to obtain consent to photograph other people, take photographs and keep a journal about their lived experiences. Following training, participants will take pictures that best represent their lives during the pandemic (including this unique holiday season).

HIGHLIGHTS

Interviews were conducted with each participant to identify salient themes related to their lived experiences.



Life goes on out the window.

I can watch.

But it is not safe for me to be out with the people
walking by and the kids playing on the street.

If people followed the rules, and kept distance,
and wore their masks, and stayed home if not
feeling well, I could.

But they do not. And I cannot.

Zhade Journal

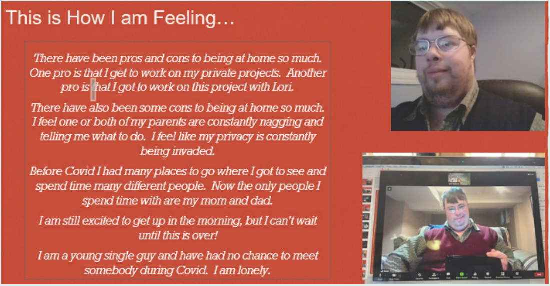
Results from this study highlight:

1. The Direct and Disproporionate Effects of COVID-19, including exacerbated fear, impacts on mental health, loss and grielf, changes and loss to services, difficulties with accessing health care, restricted autononmy and worlds becoming smaller.
2. Abeliest assumptions, including inaccessibility surrounding testing and vaccine roll-out, access to health care, and access to needed services, lacking accomodations, and restricted autonomy as a result of able-bodied asumptions.

HIGHLIGHTS

Results from this study highlight:

3. Losses assocated with social distancing and lockdown, including: social isolation as a result of missing close relationships, direct support professionals and missing work and volunteering. loss of opportunity to bes een, loss of financial ffreedom, recreational and social events, loss of opportunities for memorial services or celebration of life, and a loss of authentic engagement due to distance.



This is How I am Feeling…

There have been pros and cons to being at home so much. One pro is that I get to work on my private projects. Another pro is that I got to work on this project with Lori.

There have also been some cons to being at home so much. I feel one or both of my parents are constantly nagging and telling me what to do. I feel like my privacy is constantly being invaded.

Before Covid I had many places to go where I got to see and spend time many different people. Now the only people I spend time with are my mom and dad.

I am still excited to get up in the morning, but I can't wait until this is over!

I am a young single guy and have had no chance to meet somebody during Covid. I am lonely.

4. Changes in relationshjip, including stronger relationships, new relationships and challenges surrounding duo roles experienced by caregivers;'

5. New opportunities , including increased resilience, creaetive and new ways of staying active and keeping busy, using technology to remain connected.

HIGHLIGHTS

We hope these results will raise awareness about adults' lives with DD during the pandemic and identify areas of resilience, barriers, and challenges that need to be addressed at a broader societal level through policy and practice changes.

To learn more, please visit our facebook account at: Voices Lost in Crisis

Voices Lost in Crisis-Part 1

Voices Lost in Crisis-Part 2

Also, check us out on youtube. The links provided will send you to a presentation ont he research pocess and results.

Book Review

Working with Families to Foster Parental Capacities

"Working with families to foster parental capacities" (2023)[Cómo promover la competencia parental y el bienestar. Trabajar con las familias]. Authors: Climent Giné, Anna Balcells, Joana M. Mas, Cecilia Simón. (Please, be aware that the book is only available in Spanish).

The book is a based conceptual and methodological proposal, particularly oriented towards the practice of professionals and about how to work with families with a member with intellectual disabilities and other developmental problems.

Book Review

Working with Families to Foster Parental Capacities

The aim of the book is to argue, describe and exemplify working with families to foster their development, as well as the social and emotional well-being (quality of family life) of all its members. The focus is on family capacity-building practices, through the support of professionals, and on the empowerment of contexts (home, school, ...).

Each chapter is justified to the extent that it can truly help professionals understand different aspects of the family and community context in which they work and is intended to reflect the current state of research and evidence-based professional practices.

Link to the recording of the book presentation (in Spanish):

Working with Families to
Foster Parental Capacities

Activities at a Glance

Events to come in 2024!

- ✷ June 14: at 13:00 UTC: SIRG Annual Meeting via Zoom. Please register here to receive more information and link to join the meeting:

QOL SIRG Annual Meeting Link

- ✷ August 5-8: QOL stream of presentations in IASSIDD World Congress in Chicago
- ✷ August 5-8: QOL SIRG members dinner at a local restaurant - Details to come!
- ✷ September – November: A second QOL SIRG newsletter with highlights from Chicago congress

SPECIAL ISSUE ON QUALITY OF LIFE

Dear Colleagues,

The esteemed journal Research in Developmental Disabilities (RIDD) has recently organized a special issue focusing on "Quality of Life in Developmental Disabilities".

This special issue welcomes contributions that advance our understanding of the quality of life of people with developmental disabilities, including topics of interest such as the measurement of quality of life, interventions to improve quality of life, influential factors, methodological issues, and challenges in quality of life research, among others.

The journal's submission system is now open to receive contributions, and it will remain open until September 30, 2024. Detailed information about the special issue and submission instructions can be found at:

QOL Special Issue Instructions

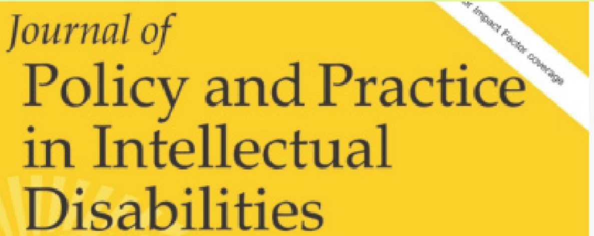
SPECIAL ISSUE ON QUALITY OF LIFE

For any inquiries regarding the relevance or suitability of a contribution, please feel free to contact the editors Gianluca Esposito (gianluca.esposito@unitn.it) or Giulia Balboni (giulia.balboni@unipg.it).

QOL Special Issue Instructions

We look forward to receiving your valuable contributions for this special issue, and we would appreciate it if you could help spread the word about this monograph and share it with other colleagues who may be interested. Best regards,

Gianluca Esposito (University of Trento) Giulia Balboni (University of Perugia) Laura E. Gómez(University of Oviedo) Eman Gaad (British Alessandro Carollo (University of Trento) Dagmara Dimitriou (University College London)



r Impact Factor coverage

Journal of
Policy and Practice
in Intellectual
Disabilities

'THROWBACK'

This past March ...

IASSIDD Quality of Life SIRG celebrated with a Reserach Roundtable. During an online session, Interntional research in Quality of Life was highlighted.

Quality of Life SIRG - Research Roundtable

IASSIDD

Quality of Life and Emotional Well-being of Families of Children with Severe Developmental Disabilities During Wartime

Presenter: Dana Roth, Beit Issie Shapiro

Bar-Ilan University

Israel

The opening keynote speaker, Dana Roth from Beit Saphiro Israel in collaboration with Bar Ilan University explored the impact of armed conflict on the quality of life of individuals with intellectual and/or developmental disabilities and their caregivers.

'THROWBACK'

During the Roundtable, a diverse number of compelling research topics were presented. Use the following link to access a recording of the research day. Roundtable Research Day

Topics for the Roundtable included:

- Quality of life of adults with Down Syndrome
- Social inclusion in neighborhoods of adults with intellectual disabilities
- A lifespan model of support for individuals with intellectual and developmental disabilities
- Social robotics support for families headed by parents with intellectual disabilities to enhance family quality of life
- Quality of life of siblings of people with intellectual and developmental disabilities
- Educational quality of life
- Quality of life and human rights implementation
- Data analysis and interpretation including:
    - The case of the Personal Outcomes Scale
    - Findings from an organizational wide evaluation of program effectiveness through the MISO measurement tool
    - Discussion about the pertinence of considering family quality of life as a paradigm.

News Section

What's up and coming in QOL Research

EDUCATION AL QUALITY OF LIFE

The research into the development of the Educational Quality of Life model will be submitted for review later this year. Educational Quality of Life (EQoL) conceptualises the phenomenon of the educational experience of high school students with a disability using a Quality of Life framework. The EQoL model acknowledges the role that student self-concept, learning support, school culture, policy and leadership, family and student identity plays in shaping the educational experience of a student with a disability. The hope is that EQoL provides a way for schools and educational authorities to implement strategies to improve the educational experience of these students, thereby improving the quality of education for all students.

Submitted by:
Mark van Ommen& Rhonda Faragher
The University of Queensland (Australia)

News Section

SOCIAL INCLUSION

CONNECTING SOCIALLY

Dr Geraldine Boland, Adjunct Assistant Professor at the UCD Centre for Disability Studies in Ireland led a research team that completed two studies that examined social inclusion of adults with intellectual disabilities in their neighbourhoods. Early findings from these studies were included in two international webinars in April 2023. The recordings of the webinars are available using the link below

Map my area: Results of a research study are presented in a video on what neighbourhood means to 10 adults with intellectual disability and experiences of engagement with people and places locally.
Volunteering and leisure: This study tested a new approach to broaden your social network through joining a new mainstream club, with support from an existing member. In this video we share what we learned about positive facilitators to overcome barriers to social inclusion. Use thi link to watch the video

CONNECTING LOCALLY

These research studies were hosted and funded by KARE, a service for people with intellectual disabilities and Kildare County Council.

Co- authors:
Anne-Marie Potter; Eilin de Paor and Professor Suzanne Guerin.

News Section

PARTICIPATORY ADVOCACY RESEARCH NETWORK

PARN is a collaboration between self-advocates living with developmental disabilities, academic and community-based researchers, and community partners (i.e., developmental support organizations and self-advocacy groups) working to build authentic collaborations to further research and advocacy goals of the developmental disability community.

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News Section

P A R N

Participatory Action Research Network

PARN is planning a 4-day co-developed and delivered Research Camp in October 2024 to bring together adults with developmental disabilities, direct support professionals, students, and established and emerging scholars to learn about inclusive and participatory research. We were successful in obtaining a SSHRC Connection Grant to allow us to prepare for and host the event and to conduct related outreach activities.

In this immersive experience, a series of workshops will be co-facilitated by thirty self-advocates, professionals, and researchers to develop and strengthen participants' (referred to as campers) .

News Section

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In this immersive experience, a series of workshops will be co-facilitated by thirty self-advocates, professionals, and researchers to develop and strengthen participants' (referred to as campers) collaborative research skills, to practice ways to engage in research that are meaningful to people living with developmental disabilities,. and to establish a network of collaborative researchers. The workshops