

FALL/WINTER NEWSLETTER

Issue 3. October, 2025



QOL-SIRG

Special Focus:

QOL RESEARCH: ASIA-PACIFIC

IN THIS ISSUE:

- [Message from the chair](#) (pg. 2)
- [QOL-SIRG at a glance](#) (pg. 3)
- Spotlight: SIRG Members research in Asia-Pacific
 - [Siblings' QOL: Project from Japan](#) (pg.5)
 - [Our Lives, Our Voices: Impact of Self-Advocacy Program](#) (pg.8)
 - [Contributors to society through volunteerism and employment](#) (pg.11)
 - [Social & Recreational Activity Support](#) (pg. 13)
- [Highlights from the past year](#) : Roundtable Discussions (pg. 14)
- Interesting Reads
 - [Family QOL Research in Asia Pacific](#) (pg. 22)
 - [Individual QOL Outcomes in Asia Pacific](#) (pg. 24)
 - [Health and Access to Health Care Asia Pacific](#) (pg. 27)
 - [What QOL Sees—and What Japan Still Doesn't: Reflections from the Frontlines](#) (pg. 29)
- Upcoming Events
 - [IASSIDD Asia-Pacific Congress](#) (pg. 34)
- [Call for Submissions](#) (pg. 37)



QOL- SIRG
NEWSLETTER

October, 2025



A MESSAGE FROM THE CHAIR

Dear Colleagues,

Those of us in the Northern Hemisphere are happy to welcome yet another Fall/Winter season. The renewal of seasons always reminds us also to renew our commitment to quality of life — not only for ourselves — but also for individuals with intellectual and developmental disabilities (IDD), their families, and the professionals who support them.

From community-led initiatives to cross-cultural research partnerships, this edition of our newsletter celebrates the voices, innovations, and resilience of researchers, advocates, and communities advancing quality of life for persons with IDD in diverse global contexts.

As we think ahead to celebrating the upcoming 2025 IASSIDD annual congress in Singapore, we especially recognize the incredible work emerging from the Asia-Pacific region.

Your continued engagement is vital to building an inclusive, global research community. Read on for highlights, key reads, reflections from past events, and exciting opportunities to connect, contribute and reflect on past and future trends in quality of life research

Warmly,

Ivan Brown

Chair, Quality of Life Special Interest Group, IASSIDD



QOL-SIRG: AT A GLANCE

Our Mission

The mission of the SIRG-QoL is to further work that enhances the quality of life for individuals with disabilities and their families through research and its application.

The QoL-SIRG goals are to:

- Hold an annual meeting to share information, and participate in other IASSIDD conferences and meetings
- Participate in collaborative activities such as conferences and publications
- Carry out collaborative projects and research
- Disseminate research and its application within IASSIDD and to the wider community through text, journal articles, special issues, and allied means
- Collaborate on ways to effect change at the societal level

Our Committee

Chair & Treasurer

Ivan Brown: ivan.brown@live.ca

Secretary

Olga Múries-Cantán: olgamc1@blanquerna.url.edu

Executive members

Courtney Bishop: courtney.bishop@durhamcollege.ca

Remco Mostert: remco.mostert@hogent.be

Yang Ting Ang: yangting.ang@minds.org.sg

Mian Wang: miwang@ucsb.edu

Preethy Samuel: preethy@wayne.edu

Members at large

Rhonda Faragher rhonda.faragher@acu.edu.au

Laura Gomez gomezlaura@uniovi.es

Val Bradley vbradley@hsri.org

Barry Isaacs barry.isaacs@surreyplace.on.ca

Luigi Croce luigi.croce57@libero.it

Heather Aldersey hma@queensu.ca



QOL SIRG NEWSLETTER

October, 2025



QOL-SIRG: AT A GLANCE

Family QOL Survey

The international family QOL survey is available. You can access a preview of the survey [here](#). To start collecting data, please contact the site administrator, Ted Myerscough tross@vex.net

Intellectual disability and non-disability (control group) versions available for download. Included: translation in 16 languages, manual, SPSS data file, and information about projects. [Download here](#).

QOL Measurement Tools

You can now access validated instruments to measure Individual QOL and Family QOL. A description and the link of the measurement tool is provided. [Access today!](#)

Instruments for measuring program-centric QOL and program effectiveness are also listed, but these instruments are licensed and need to be purchased.

See an instrument missing? Contact us at olgamc1@blanquerna.url.edu



QOL Bibliography

This annotated bibliography contains short one- to two-sentence summaries of nearly 800 articles published from 1986 to 2024 focusing on the QOL of individuals with intellectual/developmental disabilities. It will be housed on the IASSIDD website's [QOL-SIRG page](#) and will replace the existing bibliography from 2015.

Reference: Pachathu, A., Elsabagh, N., Alles, S., Clarkson, K., Jaboro, J., Manzo, L., McIntyre, E., Molaei, Pickford, H., Miah, T., Sexton, M., Yaldo, M., & Samuel, P. S. (In Press). Quality of Life (QOL) in Intellectual/Developmental Disabilities (I/DD): Annotated bibliography of publications from 1980 to 2024. White paper published by the Quality of Life, Special Interest Group, International Association for the Scientific Study of Intellectual and Developmental

SPOTLIGHT: SIRG MEMBERS RESEARCH IN ASIA-PACIFIC

Siblings QOL: Project from Japan



The Japanese Association
for Sibling Well-being
has launched!!

QOL SIRG
NEWSLETTER

October, 2025



SPOTLIGHT: SIRG MEMBERS RESEARCH IN ASIA-PACIFIC

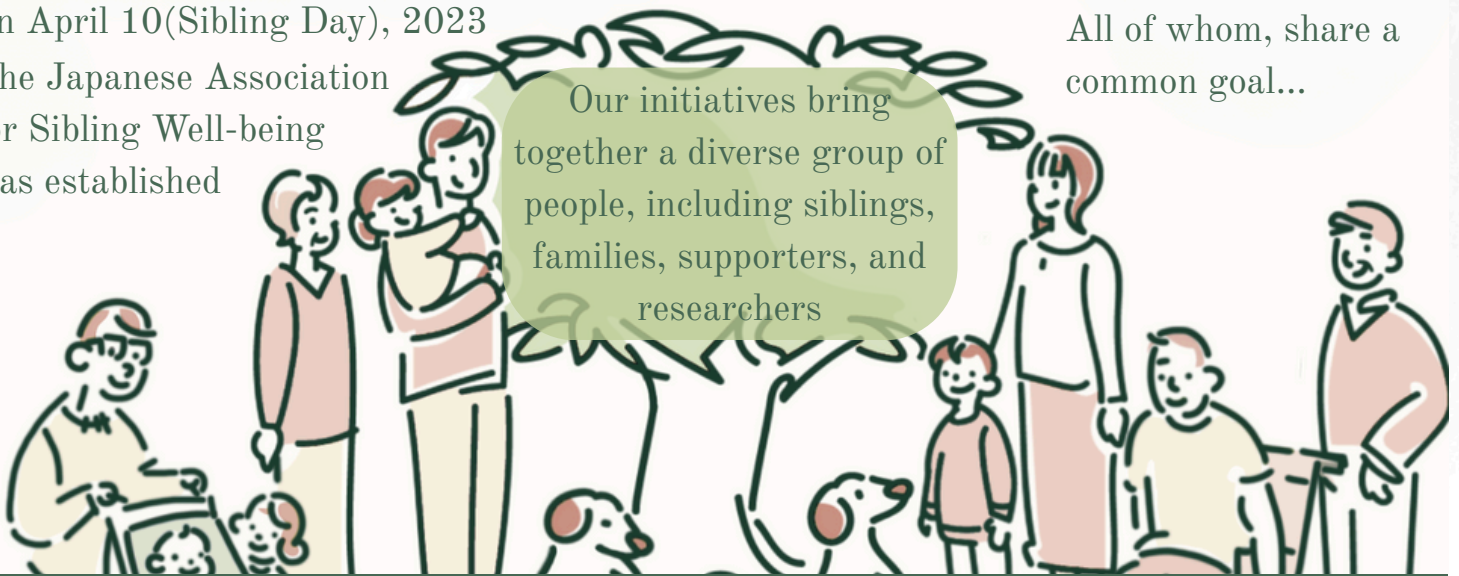
Siblings QOL: Project from Japan

On April 10(Sibling Day), 2023

The Japanese Association
for Sibling Well-being
was established

Our initiatives bring
together a diverse group of
people, including siblings,
families, supporters, and
researchers

All of whom, share a
common goal...



We strive to build a society where
siblings of individuals with
disabilities, as well as those in
various other circumstances, can
live safely and securely, anytime
and anywhere.



Images can be found [HERE](#)

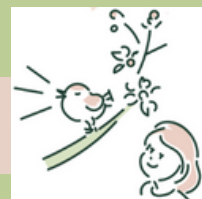


SPOTLIGHT: SIRG MEMBERS RESEARCH IN ASIA-PACIFIC



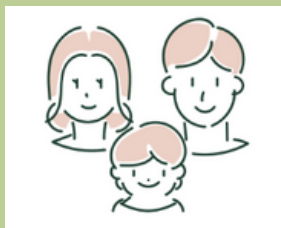
Siblings QOL: Project from Japan

Six Key Perspectives of Our Activities



1 Building connections

Activities designed to help siblings and those around them recognize that others share their concerns and that they have safe spaces to seek support and advice.



2 Educational campaigns

Efforts to raise awareness about the challenges faced by siblings and their families, fostering a supportive environment where people can help and encourage one another.

3 Creating discussion forums

Initiatives to organize and facilitate discussions where, individuals can come together to talk about issues affecting siblings.



4 Enhancing and promoting support

Activities focused on strengthening support systems for siblings.

5 Research and investigation

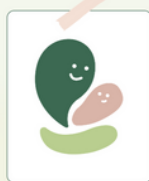
Efforts to advance research and studies related to siblings.

6 Advocacy

Initiatives aimed at creating a society where siblings, their families, and those connected to them can live securely and with peace of mind.

Contact us at:

<https://siblingjapan.com/#contact-rink>
or mabe@k-jundai.jp



Visit us (Japanese Only Site):

<https://siblingjapan.com/>
<https://siblingjapan.com/blog/>

SPOTLIGHT: SIRG MEMBERS RESEARCH IN ASIA-PACIFIC

Our Lives, Our Voices: Impact of Self-Advocacy Program on Persons with Intellectual Developmental Disability

Chong, K., Cheah, K. J., & Manokara, V. (2023)

Empowering Persons with Intellectual and Developmental Disabilities

In Singapore, the Our Lives, Our Voices (OLOV) program is breaking new ground by supporting self-advocacy among persons with intellectual and developmental disabilities. Developed by the Movement for the Intellectually Disabled of Singapore (MINDS), OLOV aligns with the UNCRPD and Singapore's Enabling Masterplans to promote autonomy, inclusion, and rights awareness.





Two-Phase Evaluation

The study evaluated both the 10-week foundational course and the graduate program using a mixed-methods design with over 180 participants, including self-advocates, caregivers, and support staff.



Key Outcomes

The OLOV program demonstrated statistically significant improvements across:

-  **Communication Skills:** clearer self-expression, initiation of conversations, and sharing of emotions and goals.
-  **Confidence to Speak Up:** increased willingness to advocate in both familiar and unfamiliar social contexts.
-  **Awareness of Rights:** emerging understanding of legal and personal rights, including speaking up against bullying and making daily choices.
-  **Ability to Practice Skills:** enhanced independence, goal setting, and application of learned skills in real-life settings.

SPOTLIGHT: SIRG MEMBERS RESEARCH IN ASIA-PACIFIC

Our Lives, Our Voices: Impact of Self-Advocacy Program on Persons with Intellectual Developmental Disability

Chong, K., Cheah, K. J., & Manokara, V. (2023)

What Helped—and What Didn't

Speech and drama-based learning, safe spaces for discussion, and caregiver involvement were vital. Challenges included abstract concepts like “rights,” lingering trauma, and inconsistent family support—especially among participants who dropped out.



Why It Matters

OLOV not only empowered individuals but also prompted changes in perceptions among caregivers and staff. The program model shows great promise for fostering social inclusion, autonomy, and a stronger sense of identity in PwIDDs—particularly in culturally conservative contexts. The authors call for continued program development, caregiver training, and policy integration to sustain these gains and expand the reach of self-advocacy.



For more information about Our Lives our Voices, click [HERE](#)

Citation: Chong, K., Cheah, K. J., & Manokara, V. (2023). Our Lives, Our Voices: Impact of Self-Advocacy Program on Persons with Intellectual Developmental Disability. *Advances in Neurodevelopmental Disorders*. <https://doi.org/10.1007/s41252-023-00372-z>

SPOTLIGHT: SIRG MEMBERS RESEARCH IN ASIA-PACIFIC

Our Lives, Our Voices: Impact of Self-Advocacy Program on Persons with Intellectual Developmental Disability



Group visit to Parliament — Program participants visiting Parliament, illustrating civic engagement and interactive learning



Keynote speaker at “Having a Say” conference showcasing the voices of PwIDDs



A snapshot from a virtual celebration like The Purple Parade, indicating ongoing community involvement



Presentation at “We Are Able!” event — A trio of self-advocates speaking publicly at a MINDS & DSA collaboration event

SPOTLIGHT: SIRG MEMBERS RESEARCH IN ASIA-PACIFIC

Impact on persons with disabilities and their families when they are contributors to society through volunteerism and employment

Cheah, K. J., Riches, V., & Manokara, V. (2024)

Work and Volunteerism as Pathways to Inclusion in Singapore

This innovative qualitative study highlights how employment and volunteerism can profoundly enhance the lives of persons with disabilities in Singapore. Conducted during the COVID-19 pandemic, the project sheds light on the personal, familial, and societal impact of contributing roles—and the structural changes needed to make them accessible.

Photovoice


Led by researchers from the Movement for the Intellectually Disabled of Singapore (MINDS) and the Centre for Disability Studies, University of Sydney, this study used interviews and photovoice with 20 adults with disabilities aged 18–49. The goals were to:


- Explore perceptions of being a “beneficiary” vs. a “contributor”
- Identify benefits, enablers, and barriers to employment and volunteering
- Recommend practical solutions to support inclusive participation


Key Findings

Transformative Participation:

Employment and volunteering improved self-confidence, social skills, and quality of life. Participants reported joy in contributing

 Persistent Barriers: Participants faced stigma, inaccessible environments, insufficient job matching, and overprotective family attitudes. A lack of formal support for volunteers with disabilities was especially notable.

 Enablers of Success: Positive work cultures, supportive job coaches, person-centred onboarding, and recognition (both informal and formal) enhanced motivation and retention. Where workplaces were inclusive, participants thrived.

 Disability Identity and Self-Perception: Many participants struggled to see themselves as contributors due to societal attitudes and internalized stigma—highlighting the need for broader cultural change

SPOTLIGHT: SIRG MEMBERS RESEARCH IN ASIA-PACIFIC

Impact on persons with disabilities and their families when they are contributors to society through volunteerism and employment

Cheah, K. J., Riches, V., & Manokara, V. (2024)

Why It Matters

This project offers a compelling case for expanding inclusive employment and volunteer opportunities. By engaging persons with disabilities as knowledge-holders, it emphasizes the importance of ecosystem-wide collaboration—from families and employers to government and service providers. The study also illustrates how participatory methods like photovoice can elevate voices often excluded from policy discourse.

Recommendations

- Improved transport and accessibility to worksites
- Structured volunteer pathways with support
- Lifelong, individualized job coaching
- Education for caregivers and employers to challenge limiting beliefs
- A culture of recognition and inclusive leadership

For more information about OMinds Employment Support click [HERE](#)

JOB MATCHING & SUPPORT SERVICE

1 Career Profiling:
Assessment of client's job readiness and suitability for open employment.

2 Job Matching:
Based on Team Hi-Job's recommendations and client's capabilities.

3 Work Assessment:
Clients are placed on a working assessment to assess their suitability for the job.

4 Job Placement & Job Support:
After a successful emplacement, Job Placement Executives will partner with employer to support each client for 1 year.

JOB SUPPORT FREQUENCY

1st & 2nd day of work:	1st month:	2nd - 4th month:	5th - 12th month:
Full Shift	Once a week	Fortnightly	Once a month

5 Graduation:
Approaching each client's 1-year milestone, Job Placement Executives set a support handover with employers and caregivers.

 TEAM@HIJOB.ORG.SG

 **64795655**
Est 35392/35395



Citation: Cheah, K. J., Riches, V., & Manokara, V. (2024). Impact on persons with disabilities and their families when they are contributors to society through volunteerism and employment. *Journal of Applied Research in Intellectual Disabilities*. <https://doi.org/10.1111/jar.13172>

SPOTLIGHT: SIRG MEMBERS RESEARCH IN ASIA-PACIFIC

Social & Recreational Activity Support for People with Intellectual Disabilities

Tamariba Tama

We are an organization based in Soja City, Okayama, Japan. After graduating from special needs schools, students often face various challenges, such as being unable to stay connected to their friends. That's where we come in...

- We encourage graduates to stay connected with friends and share joyful moments together.
- We reduce stress and support mental well-being through fun activities.
- We provide opportunities for physical activity to promote physical health.
- We encourage interaction with a variety of people to broaden experiences.
- We participate in community events to foster opportunities for social inclusion.



It's fun! No reason needed!

I look forward to it every time! That's why I can stay motivated at work!

I'm happy to see friends my age and volunteer students!

Voices of participants

Activities: walking, day camping, pizza making, music, sports, etc.



Voices of participants

I'm truly grateful for the valuable experiences I get to enjoy each time—experiences I wouldn't have just from studying at university! It's fun to interact with a variety of people, and the smiles of all the participants give me energy and encouragement!

After graduating from a special needs school, we hoped for opportunities to regularly gather and engage in activities with peers. Spending time with friends brings color and meaning to life. We are so glad to found "Tamariba Tama," where we can gain new experiences and improve our quality of life!



Voices of parents



NEKONEKKO.TAMA

HIGHLIGHTS FROM PAST MONTHS

Roundtable Discussion

We are celebrating our first roundtable of the year. This successful event took place on April 2th, 2025.

It was an insightful session where we had the opportunity to hear and learn about current research initiatives in the field of Quality of Life around the world.

[Couldn't join us this time around? That's okay! You can watch the recordings of the session HERE.](#)



HIGHLIGHTS FROM PAST MONTHS



Research Roundtable 1:

Social Inclusion Through Making Neighbourhood Connections: Experiences of Older Adults With Intellectual Disabilities of Local Volunteering and Leisure, Facilitated by Local Connectors.

Boland, G., Potter, A.-M., de Paor, E. and Guerin, S.

This qualitative study explored supporting the social inclusion of adults with IDD living in rural areas by engaging natural supporters (other than family members and paid staff). This study involved educating and preparing six local connectors—each a member of mainstream volunteering and/or leisure clubs to support six people with intellectual disabilities to join. Qualitative interviews were used to explore the experiences of local connectors. Six clusters of meaning were identifiable from content analysis including the support provided by local connectors, communication/interaction and supports for continued attendance. Rural local connectors had strong local knowledge and connections that facilitated those with disabilities to make local acquaintances

As part of a structured programme, natural supporters can be engaged to support people with intellectual disabilities to become known and make connections in their rural neighbourhoods. Implications for practice include sourcing social roles as close as possible to home for rural dwellers and the importance of flexible transport. The characteristics of local connectors and the club ethos/culture that facilitates social inclusion are identified. Policy recommendations include that local authorities offering funding to local clubs develop guidelines and education for members, with a view to embedding diverse membership as a guiding principle.

HIGHLIGHTS FROM PAST MONTHS



Roundtable Discussion

Research Roundtable 2:

Definitions and conceptualizations of Family Quality of Life Dr. Carmen T. Francisco Mora.

In the field of individual Quality of Life (QoL) research, researchers agreed at the beginning of this century to define this concept as a multidimensional construct, with subjective and objective elements and universal and cultural properties. In the field of Quality of Family Life (QoF), on the other hand, there are definitions of the concept, but not of the construct. This study offers a plausible explanation of this profound difference between the two types of definition, which lie at the heart of the theoretical models of QoL and FQoL. The QoLF definition is rooted in a subjective type of conceptualisation, whereas the QoL definition is a functional conceptualisation, which refers to the final outcome of the application of the scales.

The scope of the subjective conceptualisation of QoL is proposed from epistemological, ethical and methodological points of view. In the definition and its corresponding subjective conceptualisation lies the main analogue of the studied reality, which is the family unit. Consequently, research on QoLF must respect the definition of the concept, whatever the methodological approach adopted by scholars, since its dynamic and subjective character is concerned with the family unit and the interactions between its members.



HIGHLIGHTS FROM PAST MONTHS



Roundtable Discussion



Research Roundtable 3:

Supporting people with disabilities and their families in enhancing their self-determination within the Spanish context

This brief presentation will cover the work that our research team is doing to support people with disabilities and their families in enhancing their self-determination within the Spanish context. First, we will present the current initiatives directed towards building evaluation tools to effectively assess self-determination both within a self-report format and in a proxy format. Second, we will explain the current initiatives to understand how self-determination expresses within the home context in youth with intellectual disability and in youth with autism and finally, we will present the current endeavors to build tailored support for families to enhance their children self-determination within the home contexts.

Dr. Cristina Mumbardó



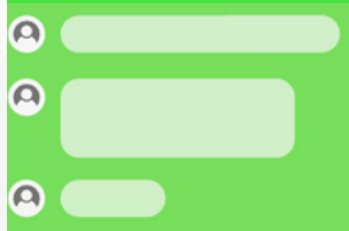
Research Roundtable 4:

The Quality of Life Triad: Three distinct ways to understand and use quality of life

The Quality of Life Triad outlines three distinct but interrelated ways to understand and apply QoL.: As a paradigm, a support tool, and a way to understand and capture lived experiences of persons with IDD. This triadic framework fills a crucial gap in QoL discourse and provides a more robust foundation for both scholarly and applied work. This brief presentation marked the beginning of a broader conversation, with Dr. Brown set to expand on the Quality of Life Triad in an upcoming lecture at the IASSIDD World Congress in Lisbon. Stay tuned for deeper insights into how this model can transform our collective efforts to enhance quality of life for people with IDD.

Dr. Ivan Brown

HIGHLIGHTS FROM PAST MONTHS



Roundtable Discussion



Research Roundtable 5:

Achieving a Person-Centered Approach Through a Focus on Optimum Quality of Life Outcomes
Joann E. Douzie

I am continuing to work on creating a dialogue on the importance of using optimum quality of life outcomes as the goal for service providers in vocational and residential settings. My Ikigai model outlines three pillars of support that can be used to organize thinking, as well as approaches. While optimum outcomes for people with IDD are improved, staff capacity and skill is developed over time through the use of a coherent model that provides a framework for the development and implementation of approaches. The global interest in Person-Centeredness can prioritize personal choice and autonomy to the extent of detrimental outcomes, which is what inspired me to develop my model.



HIGHLIGHTS FROM PAST MONTHS



Roundtable Discussion

Research Roundtable 6:

A family support project using peer mentors in the state of Michigan (USA)

Preethy Samuel, Elizabeth Janks, Nia Anderson, Sharon Milberger,
Michigan Developmental Disabilities Institute, Wayne State University

The Family Quality of Life (FQOL) approach views people with disabilities as needing support, not fixing. Aging families of people with disabilities face many problems in getting services. We know little about the best ways to support aging families. To address this knowledge gap, we tested a family support project using peer mentors in the state of Michigan. The aim of this study was to see if the FQOL of aging caregivers who participated in the project changed. We conducted quantitative analyses of data collected from 82 older caregivers before and after the study. Results indicated that the scores in global FQOL and eight of the nine domains improved. Changes in global FQOL score correlated with changes in domain-level outcomes of five FQOL domains: family, informal support, values, leisure, and community. Increased informal support could explain 16% of the variance in global FQOL. Findings point to the need to find ways to improve informal social support for aging families. Using peers in support programs can improve the mental health of aging caregivers of adults with disabilities





HIGHLIGHTS FROM PAST MONTHS

Research Roundtable 7:

Evolution of Quality of Life Research in Developmental Disabilities: A Scientometric Review

Quality of Life (QoL) reflects an individual's perception of their position in life. In the context of developmental disabilities, QoL is essential for advancing evidence-based practices, providing support, and structuring services to promote dignity and equality among people with disabilities.

Despite its critical role, QoL has not always been a primary focus in developmental disability research, often receiving less attention than other constructs. However, interest in this field has been steadily growing. In the current work, using a scientometric approach, we investigated the development of knowledge in the literature on QoL in developmental disabilities. By doing so, we conducted a comprehensive analysis using data-driven techniques and outlined the structure of knowledge in the field as well as impactful documents and major thematic domains of research.

A sample of 2141 documents and 97,547 citations was collected from Scopus and analyzed using CiteSpace software. With a document co-citation analysis, we identified the most influential publications and key research domains within the literature. Twenty-one high-impact publications were identified, primarily addressing QoL conceptualization and assessment. These documents highlighted concerns related to theoretical and conceptual aspects of QoL. Specifically, they highlight that the lack of a universally accepted definition of the construct has posed significant challenges in its measurement. Additionally, the analysis outlined nine major thematic clusters, focusing on assessment methodologies and conceptual issues (e.g., self-reported vs. proxy-reported QoL). The nine clusters reveal distinct but interconnected research themes.

HIGHLIGHTS FROM PAST MONTHS

Research Roundtable 7:

The nine clusters reveal distinct but interconnected research themes. The earliest, emerging in the 1980s, focused on deinstitutionalization, examining the transition from institutionalized care to community-based living and its impact on the QoL of people with disabilities. During the 1990s, clusters explored comprehensive assessments of QoL integrating both subjective and objective indicators, as well as self-reported and proxy-reported perspectives. Both self-reporting and assessment from others are essential for the assessment of QoL.

Additionally, research has expanded to consider QoL within family and social systems, reflecting a shift toward more holistic and context-sensitive approaches.

Quality of Life (QoL) reflects an individual's perception of their position in life. In the context of developmental disabilities, QoL is essential for advancing evidence-based practices, providing support, and structuring services to promote dignity and equality among people with disabilities.

More recent research in the 2020s has introduced the QOL support model which integrates individualized interventions with broader systemic supports, ensuring a rights-based, person-centered approach. This broader perspective suggests an evolving understanding of QoL, emphasizing the interconnectedness of individuals, families, and communities in addressing the challenges associated with developmental disabilities. The study provides a data-driven overview of how QoL has been studied in the context of developmental disabilities, highlighting the interdependence of individuals, families, and communities in ensuring a fulfilling life through the lens of QoL.

Ricardo Cavallaro¹, Alessandro Carollo¹, Giulia Balboni², Laura E. Gómez³,
Dagmara Dimitriou⁴, Gianluca Esposito¹

¹ University of Trento, Italy ² University of Bologna, Italy ³ Universidad de Oviedo, Spain ⁴ University College London, United Kingdom

INTERESTING READS

Family QOL Research in Asia Pacific

Across the Asia-Pacific region, families of individuals with intellectual and developmental disabilities (IDD) are navigating complex social, emotional, and systemic challenges that directly affect their quality of life. Recent research highlights how caregiver well-being, stress, social participation, and access to information play pivotal roles in shaping FQOL—a multidimensional construct reflecting satisfaction with emotional well-being, relationships, physical health, and access to supports.

In Saudi Arabia, Alnahdi and Schwab (2024) identified predictors of FQOL among 320 caregivers, emphasizing the influence of disability severity, type, and maternal education. Their findings call attention to the need for culturally grounded support systems, as well as the importance of tailoring interventions to demographic and contextual realities

Cheng, S., Li, J., Li, Q., Li, X., & Luo, Y. (2025). Family quality of life of parents of children with intellectual disability: Do psychological stress and parental involvement matter? *Journal of Intellectual Disabilities*, 29(2), 331–348.
<https://doi.org/10.1177/17446295241254624>

A related Korean study by Lee and Yoon (2024) underscored how caregiver strain significantly reduces quality of life by triggering mental health issues and restricting social participation. Their work advocates for integrated mental health supports and community engagement to alleviate caregiver burden.

Alnahdi, G. H., & Schwab, S. (2024). Families of children with intellectual and developmental disabilities: Variables associated with family quality of life. *Children*, 11(734).
<https://doi.org/10.3390/children11060734>

In mainland China, Cheng et al. (2025) explored how psychological stress and parental involvement intersect to influence FQOL. Their structural equation modelling revealed that while risk awareness and physical/mental responses can bolster family well-being, heightened psychological stress and misplaced optimism may undermine it. These insights highlight the necessity for mental health-informed policies and greater involvement of parents in care planning

Lee, S., & Yoon, Y. (2024). Mechanistic examination of why caregiver strain undermines quality of life: Unravelling the roles of mental health symptoms and social participation. *Asia Pacific Journal of Social Work and Development*, 34(4), 303–319.
<https://doi.org/10.1080/02185385.2023.2258856>

INTERESTING READS

Family QOL Research in Asia Pacific

Together, these studies offer a powerful regional snapshot of the factors shaping FQOL for families of persons with IDD. They call for a renewed focus on mental health, social support, caregiver training, and culturally sensitive policy reform to improve outcomes and uphold human rights across the life course.

In Taiwan, Lin et al. (2009) utilized the WHOQOL-BREF to assess caregivers of children and adolescents with ID. Their findings pointed to lower overall well-being compared to the general population, with household income, perceived health, and family support emerging as critical determinants of caregiver quality of life

Lin, J.-D., Hu, J., Yen, C.-F., Hsu, S.-W., Lin, L.-P., Loh, C.-H., Chen, M.-H., Wu, S.-R., Chu, C. M., & Wu, J.-L. (2009). Quality of life in caregivers of children and adolescents with intellectual disabilities: Use of WHOQOL-BREF survey. *Research in Developmental Disabilities, 30*(6), 1448–1458.
<https://doi.org/10.1016/j.ridd.2009.07.005>

In India, Murthy et al. (2025) focused on the information needs of caregivers of adults with IDD. A striking gap was found in caregivers' awareness of disability rights, available services, and legal protections. Older caregivers and those without English proficiency reported significantly higher unmet needs, emphasizing the urgency of multilingual, culturally accessible information campaigns.

Murthy, S., Parker Harris, S., & Hsieh, K. (2025). Information needs of caregivers of adults with intellectual and/or developmental disabilities in India. *Journal of Intellectual Disabilities, 29*(2), 306–330.
<https://doi.org/10.1177/17446295241254933>

In Mongolia, Sendmaa et al. (2024) explored the links between psychological distress and coping styles. Caregivers of people with ID experienced higher depression, anxiety, and stress scores than those supporting individuals with severe mental disorders. Positive coping strategies were associated with reduced distress but were less commonly employed by those in more stressful caregiving contexts

Sendmaa, D., Ganbaatar, N., Regzedmaa, O., Nuden, E., Chuluun, E., Luvsangenden, S.-Y., Gochoosuren, G., Myagmarjav, D., Badamdorj, O., Zuunnast, K., Dashtseren, M., Nyam, N., & Nolan, F. (2024). Association between psychological distress and coping styles in family caregivers of people with intellectual disability or chronic mental disorder in Mongolia. *Nursing Reports, 14*(4), 3524–3538.
<https://doi.org/10.3390/nursrep14040257>

INTERESTING READS

Individual QOL Outcomes Research in Asia Pacific

A rich and growing body of research across the Asia-Pacific region is offering new insight into how to support the holistic quality of life (QoL) of individuals with intellectual and developmental disabilities (IDD). This synthesis highlights recent contributions in three core areas: (1) self-determination and autonomy, (2) access to health care and therapeutic practices, and (3) physical and emotional well-being. Together, these studies underscore the value of culturally responsive, evidence-based, and person-centered approaches to inclusive practice and policy.

1 Self-Determination and Autonomy



A qualitative study from Pakistan by Khaqan et al. (2025) explored the use of dialogic literary gatherings among caregivers of children with disabilities. Findings suggest that these gatherings enhance reflective communication and shared meaning-making, indirectly contributing to more empowered caregiving relationships and potentially fostering greater autonomy for children.

Khaqan, A., Qureshi, M. A., & Hussain, T. (2025). Improving social interactions among adult carers of children with disabilities through dialogic literary gatherings: A qualitative study. *International Journal of Disability, Development and Education*. Advance online publication.

<https://doi.org/10.1080/1034912X.2024.2312825>

Wong, V. (2022). Study protocol for a randomized controlled trial evaluating the effectiveness of a group-based self-determination enhancement intervention for adults with mild intellectual disability. *BMC Psychology*, 10, 281. <https://doi.org/10.1016/j.ridd.2009.07.005>

In Hong Kong, Wong (2022) launched a randomized controlled trial evaluating a group-based intervention aimed at enhancing self-determination in adults with mild ID. The program—grounded in self-determination theory—promotes autonomy, self-regulation, and personal goal setting, with an optional caregiver module to strengthen supportive environments. If successful, this model may serve as a scalable intervention for Chinese-speaking populations across the region.

INTERESTING READS

Individual QOL Outcomes Research in Asia Pacific

2 Physical Well-Being

A significant thread in recent research emphasizes the role of physical activity and inclusive sport in improving cognitive, emotional, and physical health for individuals with IDD

Xiao, R., Xu, P., Liang, X.-L., Zou, Z., Zhong, J.-G., Xiang, M.-Q., & Hou, X.-H. (2024). Effects of the Special Olympics unified sports soccer training program on executive function in adolescents with intellectual disabilities. *Journal of Exercise Science & Fitness*, 22(1), 103–110.
<https://doi.org/10.1016/j.jesf.2023.12.006>



Yang, W., Yu, J. J., Wong, S. H.-S., Sum, R. K.-W., Li, M. H., & Sit, C. H.-P. (2022). The associations among physical activity, quality of life, and self-concept in children and adolescents with disabilities: A moderated mediation model. *Frontiers in Pediatrics*, 10. <https://doi.org/10.3389/fped.2022.947336>

Xiao et al. (2024) found that participation in Special Olympics Unified Soccer training improved executive functioning in adolescents with ID, suggesting that team-based physical engagement may enhance not only fitness but also cognitive flexibility and self-regulation.



In a Hong Kong-based study, Yang et al. (2022) used structural equation modeling to demonstrate that physical activity significantly improves self-concept, which in turn mediates improvements in QoL among youth with physical and intellectual disabilities. Moderating factors such as gender and parental education were also influential.

INTERESTING READS

Individual QOL Outcomes Research in Asia Pacific

In China, Zhao et al. (2024) conducted a randomized trial comparing aquatic exercise and floor curling among children with ID. Both activities led to significant improvements in lower limb muscle strength and balance—key contributors to mobility, confidence, and participation in daily activities.

Zhao, P., Zhu, G., Chen, S., Pan, Y., Chen, K., Huang, L., & Guo, L. (2024). Effects of Aquatic Exercise and Floor Curling on Balance Ability and Lower Limb Muscle Strength in Children with Intellectual Disabilities: A Pilot Study in China. *Children*, 11(1), 85. <https://doi.org/10.3390/children11010085>

Physical Well-Being

2



Shen et al. (2024) evaluated a remote, family-based physical activity program for adolescents with IDD. Results showed increased physical activity levels and enhanced self-reported QoL, validating the feasibility and impact of virtual interventions.

Shen, X., Huang, P., Su, M., Liu, Z., Liu, Q., Guo, Y., & Zheng, L. (2024). Impact of remote collaboration-based family physical activity on activity levels and quality of life in children with intellectual developmental disabilities. *Frontiers in Public Health*, 12. <https://doi.org/10.3389/fpubh.2024.1464099>



INTERESTING READS

QOL: Health and Health Care Research in Asia Pacific

A growing body of international research is deepening our understanding of how health care systems, practices, and relationships shape the quality of life for individuals with intellectual and developmental disabilities (IDD). This synthesis highlights recent contributions in the area of access to health care and health care practices, illustrating how structural conditions, clinician attitudes, and person-centered communication influence health outcomes and experiences. Together, these studies emphasize the need for inclusive, rights-based health care systems that are attuned to both relational and systemic equity.

From a systems perspective, Wyborn et al. (2025) introduced a co-designed mapping review protocol to assess the quality of health care for people with intellectual disabilities in Australia. The review seeks to evaluate the extent and nature of evidence addressing health inequities, access barriers, and organizational practices. Its emphasis on involving individuals with lived experience in the review process marks an important shift toward participatory health research that centers inclusion and responsiveness.

Wyborn, L., Witham, R., Fogarty, A., Wark, S., & Trollor, J. (2025). Quality of healthcare for people with intellectual disability: A mapping review protocol of the evidence from Australia. *BMJ Open*, 15(4), e083597. <https://doi.org/10.1136/bmjopen-2024-083597>

In Taiwan, Chou et al. (2025) conducted a qualitative study on the expectations of people with visual and intellectual disabilities regarding ophthalmic care. Participants emphasized the importance of respectful, clear communication, including nonverbal cues such as smiling and speaking slowly. The study reveals critical gaps in provider training and highlights the need for more inclusive, disability-aware health care environments.

Chou, Y.-C., Lo, I. C.-H., & Chiu, T.-Y. (2025). 'Smiling and talking slowly': A qualitative study on the ideal ophthalmologist from the perspective of people with visual and intellectual disabilities in Taiwan. *Health & Social Care in the Community*, 33(1), p.p. 165–173. <https://doi.org/10.1111/hsc.14238>

INTERESTING READS

QOL: Health and Health Care Research in Asia Pacific

Kim et al. (2025) piloted a garden-based healing program in Korea for young adults with IDD. The program not only promoted emotional regulation and social participation but also served as a meaningful space for self-reflection and therapeutic engagement.

Kim, S., Park, Y., & Choi, H. (2025). Qualitative evaluation of a garden-based healing and learning program for young adults with intellectual disabilities. *Journal of Developmental and Physical Disabilities*. Advance online publication. <https://doi.org/10.1007/s10882-024-09915-2>

Desroches, M.-L., Wilson, N. J., Fortune, N., & Vickery, K. (2022). Nurses' attitudes and emotions toward caring for adults with intellectual disability: An international scoping review. *Journal of Intellectual & Developmental Disability*, 47(4), 370–383. <https://doi.org/10.3109/13668250.2020.1857697>

An international scoping review by Desroches et al. (2022) examined the emotional responses and attitudes of nurses toward caring for adults with intellectual disabilities. While many nurses expressed compassion and ethical commitment, feelings of anxiety, fear, and frustration were also prevalent—often attributed to a lack of training, confidence, or institutional support. The review emphasized the need to embed inclusive care competencies into nursing education and to develop workplace cultures that support relationship-based and rights-affirming care.

In Turkey, Avci (2024) examined the relationship between sleep quality and mental health in adolescents with mild ID. Poor sleep quality was associated with heightened symptoms of anxiety and depression, reinforcing the importance of integrating sleep hygiene education into routine health monitoring and school-based wellness programs.

Avci, B. (2024). Mental health problems among adolescents with mild intellectual disability and relation to sleep quality. *Community Mental Health Journal*. Advance online publication. <https://doi.org/10.1007/s10597-024-01241-x>

INTERESTING READS

What QOL Sees—and What Japan Still Doesn't: Reflections from the Frontlines

Mizuho Tatsuta, Ph.D.

Faculty of Sociology, Ryukoku University, Japan

As the **5th IASSIDD Asia-Pacific Congress** convenes in Singapore, I would like to share Japan's experience with the Personal Outcomes Scale (POS) 3, together with some candid reflections on the everyday realities faced by persons with intellectual disabilities within Japan's welfare system. These stories reveal both emerging possibilities and enduring challenges—an open invitation to deepen our dialogue with colleagues across Asia and beyond.

Who Decides What Makes a 'Good Life'?

Shinya Tateiwa, a leading sociologist in Japanese disability studies, once reminded us: 'If we don't need to measure QOL, perhaps we shouldn't. But there are times when we must.' 'That a good life is desirable is self-evident. But deciding what constitutes a "good life" is an entirely different matter.'

This question has become more pressing than ever in Japan's disability welfare landscape. Policy documents emphasise supported decision-making, community transition, and inclusive community building. Yet, in everyday practice, these ideals often coexist with deeply rooted structural challenges that resist easy change.

Cultural Context: A Family-Centred Structure

In Japan, about 80% of adults with intellectual disabilities under the age of 65 live with family members¹. This reflects cultural values—but also structural constraints. When aging parents can no longer provide care—a situation now referred to as the '80-50 problem' (parents in their 80s, adult children in their 50s)—the only available option has often been abrupt relocation to an institutional setting far from familiar communities.

In recent years, group homes have increased rapidly. While the 'community transition' policy focuses mainly on moving people from institutions to group homes, in practice, the available living options remain narrowly confined to three: institutions, group homes, or living with family. Even when individuals wish to move into a group home, families sometimes object—believing institutional care to be 'safer.' This family-centred culture arises from deep care and love, but it can also produce structures that unintentionally suppress individual voices.

INTERESTING READS

What QOL Sees—and What Japan Still Doesn't: Reflections from the Frontlines

Mizuho Tatsuta, Ph.D.

Faculty of Sociology, Ryukoku University, Japan

Behind the Doors: What 'Community Living' Really Looks Like

In Kyoto, where I work, group homes have proliferated—driven in part by private-sector entry into the welfare field. More people are moving in as their parents age, yet beneath this surface of progress lie unsettling realities. Not all homes operate this way, but I often hear concerning stories:

Ms A's home: When her sibling wanted to visit with a birthday cake, they were told that 'outsiders cannot enter private rooms without permission.' Visits were allowed only if accompanied by her support staff from outside the home. Is this truly *her home*?

Mr B's home: Because night-shift staff leave at 7:00 a.m., all residents must have breakfast together at 6:00—regardless of their personal rhythm or preference.

Mr C's home: Although an adult, he is prohibited from drinking or smoking indoors. Even in summer heat or winter cold, he must go outside to a convenience store to enjoy a beer or cigarette.

Ms D's home: When she said she wanted to spend weekends at her family home, staff discouraged it—saying it would make her 'homesick' or 'disrupt her routine.' In reality, her absence would mean a temporary loss of income for the home.

Although these are called 'community living' arrangements, **organisational convenience often takes precedence over individual choice**. A fundamental question arises: *Whose life is this, really?*

INTERESTING READS

What QOL Sees—and What Japan Still Doesn't: Reflections from the Frontlines

Mizuho Tatsuta, Ph.D.

Faculty of Sociology, Ryukoku University, Japan

The 'Family Consent' Barrier in POS Research

We are currently working to standardise the Japanese version of the POS. Throughout this process, one recurring challenge has been that **'family consent' is prioritised over 'individual consent.'**

Support staff often express concerns such as:

'It's burdensome to explain to families.'

'We don't want to worry parents.'

'What if they complain?'

Even when individuals themselves wish to participate, their involvement is sometimes withdrawn because 'the family objects' or 'parental approval hasn't been obtained.'

This exposes a serious paradox: While 'person-centred support' and 'supported decision-making' are officially emphasised, in practice, **family and organisational convenience still override individual autonomy.**

We must ask ourselves again: **Whose QOL are we measuring? Whose life are we supporting?**

'Community Transition' Only Has Meaning When It Improves QOL

Japan's policies promote 'community transition' from institutional settings. However, arguments justifying continued institutionalisation—on the grounds of severe disability or advanced age—remain widespread. What is missing from these debates is a simple, crucial question: **Has this person's quality of life actually improved?**

Without a QOL perspective, 'community transition' becomes little more than a change of address—not a transformation in lived experience.

INTERESTING READS

What QOL Sees—and What Japan Still Doesn't: Reflections from the Frontlines

Mizuho Tatsuta, Ph.D.

Faculty of Sociology, Ryukoku University, Japan

Seeds of Change: POS Interviewer Training

In May 2024, Japan held its first POS interviewer training, led by Marco Lombardi and Remco Mostert from HOGENT University (Belgium). About 50 participants—including welfare practitioners, psychologists, and researchers—took part. Their reflections reveal shifting perspectives:

'Traditional assessments were support-led, focusing on identifying problems. POS is a dialogue—exploring together what the person values.'

'I realised I only asked about things I could support. I was imposing my own judgments.'

'I thought I was listening to the person, but I was actually prioritising family opinions.'

These honest insights expose challenges shared across Japan's welfare field, but they also show readiness for transformation. One participant's words were especially memorable:

'I never knew that getting to know someone could be this fascinating. I don't want to forget this feeling.'

POS is not merely an assessment tool—it is a **doorway to genuine human connection.**



Remco (left) and Marco (right) during their visit to Ryukoku University.

INTERESTING READS

What QOL Sees—and What Japan Still Doesn't: Reflections from the Frontlines

Mizuho Tatsuta, Ph.D.

Faculty of Sociology, Ryukoku University, Japan

From Japan to Singapore—and Beyond

The stories from Japan raise questions we must continue to explore together:

- How can we respect both cultural values and individual voices when they seem to conflict?
- What does 'community living' truly mean when it is driven by the person, not by systems or support workers?
- How can QOL perspectives lead to real changes in people's everyday lives?

Assessing QOL is not just about numbers or scales. It is about noticing what we have taken for granted, listening to voices we have long overlooked, and discovering possibilities we have yet to imagine.

This work belongs to all of us. Let us continue it together.

References:

1. Ministry of Health, Labour and Welfare. (2023). *Comprehensive survey of living conditions of persons with disabilities 2022: Summary report*. Tokyo, Japan (in Japanese).
2. Tateiwa, S. (1999). *Important and dangerous QOL*. In Editorial Committee of the 21st Century Medical Forum (Ed.), *Thinking about QOL: 21st Century Medical Forum* (pp. 142–147). 21st Century Medical Forum (in Japanese).
3. van Loon, J., van Hove, G., & Schalock, R. L., & Claes, C. (2008). *Personal Outcomes Scale*. Ghent, Belgium: University of Ghent.



Scene from the POS interviewer training session in Kyoto.

Contact:

mtatsuta@soc.ryukoku.ac.jp

QOL SIRG

NEWSLETTER

October, 2025



UPCOMING EVENTS

IASSID 5th Asia Pacific- Congress

Person-centricity as an Approach to Well-being of People with Intellectual and Developmental Disabilities

Pre-congress workshops: October 14th, 2025

Main Event: October 15-17th, 2025

[Find out more](#)

Taking place at the Holiday Inn Atrium in Singapore

Register today or visit the webpage for more information

[Register Today](#)

Looking for something to do while in Singapore?

Don't miss these opportunities

1. Explore Bugis Junction:

- Bugis Street Market: Over 800 stalls selling souvenirs, fashion, and local snacks like kaya toast and curry puffs.
- Bugis Junction & Bugis: Blend of heritage shophouses and modern malls filled with boutiques, eateries, and covered walkways
- Haji Lane: Quirky indie boutiques, colorful street art and café culture

[Check out Bugis Street and Junction HERE](#)



UPCOMING EVENTS

IASSID 5th Asia Pacific- Congress

Looking for something to do while in Singapore?

Don't miss these opportunities

2. Visit Cultural & Religious Landmarks

- Kwan Im Thong Hood Cho Temple: Beautiful pre-WWII Chinese temple dedicated to the Goddess of Mercy
- Sri Krishnan Temple: Located right beside Kwan Im, a vibrant Hindu spot with ornate carvings
- Sultan Mosque: Iconic with golden domes, free entry (dress respectfully required), and nearby Ramadan bazaars
- Hajjah Fatimah Mosque: Unique fusion of Islamic & European architecture built in 1846
- Giok Hong Tian & Hock Teck Tong Temples: Hidden gems just a 5-minute walk from the hotel

3. Riverside & Garden Escapes

- Robertson Quay & Clarke Quay: Quaint riverside dining, coffee hangouts, and lively nightlife
- Gardens by the Bay & Singapore Flyer: Slightly farther, yet reachable by MRT/taxi—famous landmarks with breathtaking views



UPCOMING EVENTS

IASSIDD 5th Asia Pacific- Congress

Looking for something to do while in Singapore?
Don't miss these opportunities



4. Dive Into Arts & Museums

- MINT Museum of Toys: Nostalgic collection of 8,000+ vintage toys across five floors
- Singapore Art Museum / National Design Centre: Contemporary art exhibits & design showcases in hip Bras Basah–Bugis
- Objectifs Centre for Photography & Film: Independent arts space featuring exhibitions and film screenings
- Singapore City Gallery: Fascinating city-planning model and interactive exhibits

5. Food & Dining

- Albert Centre Market & Hawker Stalls: Dive into local delights like laksa, chicken rice, and carrot cake
- Suki-Ya at Bugis: All-you-can-eat Japanese hotpot buffet
- Memo Cafe: A modern café nestled in Robertson Quay. The perfect place for catching up with friends over a coffee or healthy lunch bowl or just chilling with a glass of wine.

6. Unusual Evening & Chill Spots

- The Projector – Indie & art-house cinema in Golden Mile Tower, plus rooftop bar vibes
- Maison Ikkoku – Craft cocktails upstairs, café downstairs—award-winning and atmospheric



CALL FOR SUBMISSIONS

We would love to hear from you!

The Quality of Life Special Interest Research Group (QOL SIRG) invites submissions for the upcoming Spring/Summer 2026 issue of our international newsletter. We welcome contributions from researchers, practitioners, self-advocates, family members, and organizations working to improve the quality of life for individuals with intellectual and developmental disabilities (IDD) around the globe.

What are we looking for?

Our newsletter will spotlight emerging research, innovative practices, and lived experiences that advance quality of life across diverse cultural, policy, and service contexts. We especially encourage submissions that address quality of life domains such as:

- Emotional, material and/or physical well-being
- Social inclusion, community participation and/or interpersonal relationships,
- Rights, autonomy and/or self-determination
- Standards of living, standards of care, and/or access to services
- Individual, Family and/or Sibling Quality of Life
- Policy and Practice

Deadline:
February 17th 2026

What should I submit?

We welcome the following types of submissions:

- Brief research summaries or project updates (200–400 words)
- Reflections or first-person narratives from self-advocates and family members
- Community, policy, or organizational practice spotlights
- Visual contributions (photos, infographics, artwork, etc.)
- Announcements of recent publications, awards, or upcoming events
- Calls for collaboration or research participation

Interested?

Please email your submission (Word or PDF format preferred) to: Courtney Bishop at cbishop@brocku.ca

Include your name, affiliation, and a brief bio (50 words max) if relevant.