QUALITY OF LIFE IN INTELLECTUAL & DEVELOPMENTAL DISABILITIES

ANNOTATED BIBLIOGRAPHY

1986-2024

PREPARED FOR

QOL Special Interest Research Group,
International Association for the
Scientific Study of Intellectual and/or
Developmental Disabilities (IASSIDD)

PREPARED BY

Preethy S. Samuel, Anushya Pachathu, Nawal Elsabagh,
Elizabeth McIntyre, Shehani Alles, Rayhauneh Molaei,
Heidi Pickford, Kelly Clarkson, Jacqueline Jaboro, Lauren Manzo,
Taslima Miah, Michaela Sexton, & Marcella Yaldo.

Quality of Life in Intellectual & Developmental Disabilities: Annotated Bibliography (1986-2024)

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The authors have made every effort to conduct a thorough search of published literature. Please direct errors or omissions to:
Dr. Preethy S. Samuel: preethy@wayne.edu

About this book

An annotated bibliography of more than 800 books, book chapters, and journal articles published from 1986 to 2024 focusing on the quality of life of individuals with intellectual and/or developmental disabilities.

An invaluable resource for scholars, professors, researchers, and students.

Suggested citation (APA 7th)

Samuel, P. S., Pachathu, A., Elsabagh, N., McIntyre, E., Alles, S., Molaei, R., Pickford, H., Clarkson, K., Jaboro, J., Manzo, L., Miah, T., Sexton, M., & Yaldo, M. (2025). *Quality of life in intellectual & developmental disabilities: Annotated bibliography (1986-2024).* International Association for the Scientific Study in Intellectual and Developmental Disabilities (iassidd.org/sirgs/quality-of-life).

Cover design by Preethy S. Samuel.

An electronic publication of the Quality of Life Special Interest Research Group (SIRG) of the International Association for the Scientific Study of Intellectual and Developmental Disabilities.

Quality of Life in Intellectual & Developmental Disabilities: Annotated Bibliography (1986-2024)

	1986	**Summary of Work**
1	Landesman, S. (1986). Quality of life and personal life Satisfaction: Definition and measurement issues: Guest editorial. *Mental Retardation*, *24*(3), 141.	
2	Schalock, R. L. (1986, May). Current approaches to quality of life assessment. Paper presented at the Annual Meeting of the American Association on Mental Deficiency, Denver, CO.	
3	Schalock, R. L., & Jensen, C. M. (1986). The study focuses on assessing the goodness-of-fit between individuals and their environments. *Journal of the Association for Persons with Severe Handicaps, 11,* 103-109. https://doi.org/10.1177/154079698601100203	The article outlines assessment & quantification procedures involved in determining goodness-of-fit between individual & environment using a 3-step procedure: (1) assess a person's behavioral capabilities, (2) determine performance requirements within a person's environment, & (3) compute a GOF index. Concurrent validity & correlational analyses conducted to describe relationships among criterion groups, GOFIs, & other outcomes. Potential uses of the GOFI procedure for completing discrepancy analyses, person- and setting-intervention strategies, & formulating program development & evaluation strategies are discussed.

	1988	**Summary of Work**
1	Brown, R. I. (1988) Quality of Life for Handicapped People, A Series in Rehabilitation Education, Volume 3. Beckenham, Kent: Croom Helm.	
2	Schalock, R L , & Heal, L W (1988). Research in quality of life. Current status and policy recommendations. Unpublished manuscript prepared for the Administration on Developmental Disabilities.	
3	Turnbull, A. P. (1988). The challenge of providing comprehensive support to families. *Education and Training in Mental Retardation*, 261-272. https://www.jstor.org/stable/23889267	This paper focuses on expectations & possibilities created by recent legislation for comprehensive family support by outlining Part-H goals & expectations for family support, suggesting outcomes for a family support program, describing how outcomes might be translated into assessment & service options, and a challenge for change in the future. The author also shares her personal experiences as a parent of a 20-year-old son with IDD.

	1989	**Summary of Work**
1	Brown, R. I. (1989). Aging, disability and quality of life: A challenge for society. *Canadian Psychology / Psychologie canadienne, 30*(3), 551–559. https://doi.org/10.1037/h0079832	This article examines transfer of knowledge from the field of IDD to aging, to avoid similar pitfalls in service provision. QOL raises issues associated with cognition, emotion, and personal attributes of lifestyle. This paper argues for a re-evaluation of professional services in the QOL context that can lead to the client playing a much more dominant role in decision-making within a delivery service oriented to the individual's personal and familiar environment.
2	Brown, R.I. (1989). Quality of Life for disabled learners. In N. Csapo (Ed.). *Special Education Across Canada: Challenges for the 90s*. Vancouver, BC. Center for Human Development & Research.	
3	Brown, R.I., Bayer, M.B., & MacFarlane, C. (1989). Rehabilitation Programmes: Performance and Quality of Life of Adults with Developmental Handicaps. Toronto, Ontario: Lugus Productions Ltd.	
4	R.L. Schalock (1989). The concept of quality of life in community-based mental retardation programs. *Issues in Special Education and Rehabilitation, 5,* 5-32.	
5	R. L. Schalock, K.D. Keith, K. Hoffman, & O. Karan (1989). Quality of life: Its measurement and use. *Mental Retardation. 27 (1),* 25-31. PMID: 2927324	

	1990	**Summary of Work**
1	Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, *46*(6), 722-730. https://doi.org/10.1002/1097-4679(199011)46:6<722::aid-jclp2270460605>3.0.co;2-6	Comparison of stress of mothers of children with autism (n = 24), cystic fibrosis (n = 24), & typically developing children (n = 24) using the Questionnaire on Resources & Stress short form showed that family stress is greatest for families of children with autism.
2	Brown, R. I., & Brown, P. M. (1990). Quality of life: Community intervention. In C. Denholm (Ed.), *Proceedings of the Canadian Down Syndrome Conference.* Victoria, BC: Canadian Down Syndrome Society	
3	Conroy, J.W. & Feinstein, C.S. (1990). Measuring quality of life: Where have we been? Where are we going? In R.L. Schalock & M.J. Begab (Eds.), *Quality of Life: Perspectives and issues* (pp. 227-233). Washington: American Association on Mental Retardation. ED323698.pdf	This chapter proposes that future QOL measurement should include an outcome orientation, which evaluates the quality of any service by measuring the benefits experienced by consumers of that service.
4	Keith, K.D. (1990). Quality of life: Issues in community integration. In R.L. Schalock & M.J. Begab (eds), *Quality of life: Perspectives and Issues* (pp. 93-99). Washington: American Association on Mental Retardation. ED323698.pdf	This chapter describes aspects of a personal lifestyle that contribute to QOL, for persons with ID, moving toward full community integration.
5	Schalock, R.L. (1990). An international perspective on quality of life: Measurement and use. [Paper presentation]. *Annual Meeting of the American Association on Mental Retardation.* Atlanta, GA. https://eric.ed.gov/?id=ED324872	Comparison of QOL perspectives of individuals receiving IDD services using the QOL questionnaire with 92 individuals from Australia, Germany, Israel, & China and 552 individuals from Nebraska & Colorado. Findings indicate that the QOL concept in habilitation services can be used cross-culturally to foster international QOL-oriented policy, practice, & research.
6	Schalock, R.L. (1990). Attempts to conceptualize and measure quality of life. In R.L. Schalock & M.J. Begab (1990) (Ed.), *Quality of life: Perspectives and issues* (pp.141-148). Washington: American Association on Mental Retardation. https://psycnet.apa.org/record/1990-98020-008 *[Translated into Japanese in 1995]*	A summary of early attempts at conceptualizing & measuring QOL from the social science perspective using social & psychological indicators, goodness of fit, social policy, & disability perspectives of people with IDD.
7	Schalock, R. L. (1990). *Quality of life: Perspectives and Issues.* Washington, DC: American Association on Mental Retardation. https://eric.ed.gov/?id=ED323698	This book examines QOL concept in persons with IDD, with a specific focus on personal perspectives, service delivery issues, assessment & measurement issues, & future of QOL as a concept.
8	Scherer, M. (1990). Assistive device [AD] utilization and quality of life in adults with spinal cord injuries or cerebral palsy two years later. *Journal of Applied Rehabilitation Counseling, 21*(4), 36-43. http://doi.org/10.1891/0047-2220.21.4.36	A longitudinal study that tracked the benefits of AD utilization on functioning, temperament, & QOL (7 adults with SCI & 5 adults with CP) reports that functional capability & temperament of those with CP improved over time whereas most with SCI seemed to become less adjusted in several areas. While SCI participants who used ADs continued to display the best overall functioning, SCI non-users

reported functional declines over time with the gaps between them and SCI AD users widening.

	1991	**Summary of Work**
1	Brown, R. I. (1991). Quality of life for adults with developmental handicaps: Some issues for discussion. In D. Baine (Ed.), *Instructional Environments for Learners having Severe Handicaps* (pp.109-117). Edmonton, AB: University of Alberta Printing Services. https://eric.ed.gov/?id=ED344388	The author concludes Quality of life as a holistic concept covering all domains of an individual's environment and functioning and 40 participants in community-based program showed greater gains in several areas than did individuals remaining in traditional rehabilitation settings.
2	Conway, R. N. (1991). Have changes in educational services for students with intellectual disability resulted in advances in those students' quality of life? *Australia & New Zealand Journal of Developmental Disabilities*, *17*(3), 271-283. https://doi.org/10.1080/07263869100034611	Educational changes that include policy functioning, teaching strategies, & integration has resulted in an improvement in QOL of Australian students with ID. Further research needed in areas of curriculum education that is specific to meeting each student’s individual needs.
3	Cummins, R. A. (1991). The comprehensive quality of life scale-intellectual disability: An initial report. *Australia and New Zealand Journal of Developmental Disabilities*, *17*(2), 259-264. https://eric.ed.gov/?id=EJ447309	Provides a description of the *Comprehensive QOL Scale* used with individuals with ID using two added components & modifications to measure subjective & objective dimensions.
4	Schalock, R. L. (May, 1991). The concept of quality of life in the lives of persons with mental retardation. Annual Convention of the American Association on Mental Retardation. https://eric.ed.gov/?id=ED337924	This conference paper evaluated the impact that QOL perception has on a person with IDD with indicators of independence, productivity, community integration, & satisfaction. Findings indicate the need to establish QOL programs to maximize individual QOL.
5	Sinnott-Oswald, M., Gliner, J. A., & Spencer, K. C. (1991). Supported and sheltered employment: Quality of life issues among workers with disabilities. *Education & Training in Mental Retardation*, *26*(4), 388-397. https://www.jstor.org/stable/23878702	Testing of a new QOL survey with individuals with disabilities in a sheltered workshop (n = 10), supported community employment (n = 10), & on individuals without disabilities (n = 9) indicated that supported employment was associated with better leisure involvement, self-esteem, mobility, perceptions of job skills, & change of income.
6	Sloper, P., Knussen, C., Turner, S., & Cunningham, C. (1991). Factors related to stress and satisfaction with life in families of children with Down's syndrome. *Journal of Child Psychology and Psychiatry*, *32*(4), 655-676 https://doi.org/10.1111/j.1469-7610.1991.tb00342.x	Analysis of 181 families of children with Down syndrome determined descriptor variables (child variables, family characteristics, parental & family resources, & coping factors), which resulted in parental stress & low satisfaction in life of both parents with the use of self-reported booklets & open-ended interviews.

	1992-1993	**Summary of Work**
1	Brown, R. I., Bayer, M. B. & Brown, P. M. (1992) *Empowerment and developmental handicaps: Choices and quality of life*, Toronto, Ontario: Captus Press and London: Chapman & Hall. https://www.semanticscholar.org/paper/Empowerment-and-developmental-handicaps-%3A-choices-Brown-Bayer/3d0c6eda7cb74487cc0249be9bd8ea5b8c116458	Rehabilitation programs study client interventions consisting of team experiences & application of procedures with a specific agency, with results of intervention being an analysis & discussion of group results.
2	Keith, K. D., & Schalock, R. L. (1992). Assessing the quality of student life. *Issues in Special Education and Rehabilitation*, *7*(2), 87-97. https://psycnet.apa.org/record/1998-01738-008	A brief report of the psychometric properties & initial normative data from the Quality of Student Life Questionnaire from 22 junior & 175 senior high students in special education with a discussion on three potential uses of quality of student life data.
3	Kozleski, E. & Sands, D. (1992). The yardstick of social validity: Evaluating quality of life as perceived by adults without disabilities. *Education and Training in Mental Retardation, 27*(2), 119-131. https://kuscholarworks.ku.edu/bitstream/handle/1808/25645/23878679.pdf?sequence=1	QOL surveys (Consumer Satisfaction Survey) designed for adults with DDs when administered to 133 adults without disabilities, indicated that some QOL indicators can act as an inhibitor to an increase in QOL satisfaction.
4	Brown, R. (1993). Quality of life issues in aging and intellectual disability. *Australian and New Zealand Journal of Developmental Disabilities*, *18*(4), 219. https://doi.org/10.1080/07263869300034991.	As lifespan of people with ID increases there are new rehabilitation challenges. This article discussed these developments in relation to QOL with suggestions for these emerging challenges.
5	Harner, C. & Heal, L. (1993). The multifaceted lifestyle satisfaction scale (MLSS): Psychometric properties of an interview schedule for assessing personal satisfaction of adults with limited intelligence. *Research in Developmental Disabilities*, *14,* 221-236. https://doi.org/10.1016/0891-4222(93)90032-F	MLSS was tested for reliability and validity by administering it with individuals with IDD (structured interviews) to assess their satisfaction in home, community, relationships, leisure, employment, & self-direction.
6	Raphael, D., Renwick, R., & Brown, I. (1993). Studying the lives of persons with developmental disabilities: Methodological lessons from the Quality of Life Project. *Journal on Developmental Disabilities*, *2*(2), 30-49.	Although QOL information provided by consumers with DD is important, they are infrequently included. They were consulted with directly in this ongoing project that illustrates data- gathering challenges and presented a novel approach to studying the QOL of persons with DD.
7	Schalock, R. L. (1993). Viewing quality of life in the larger context. *Journal of Intellectual and Developmental Disability*, *18*(4), 201-208. https://psycnet.apa.org/record/1994-26002-001	Four aspects of the QOL concept that affect policy development & habilitation services for people living with ID are discussed in the context of service delivery, program evaluation & policy, & program development.
8	Schalock, R. L., & Keith, K. D. (1993; 2004). *Quality of Life Questionnaire*. Worthington, OH: IDS Publishing. https://psycnet.apa.org/doiLanding?doi=10.1037%2Ft10624-000	Description of the QOL questionnaire's reliability to measure QOL of people with an IDD using a small sample size.

	1994	**Summary of Work**
1	Beck, I. & König, A. (1994). Quality of life for mentally retarded people in Germany: An overview of theory and practice. In D.A. Goode (Ed.), *Quality of life for persons with disabilities: International perspectives and issues* (pp. 103-125). Cambridge: Brookline Books.	Book chapter on international perspectives on QOL
2	Brown, R. I. (1994). Down syndrome and quality of life: Some challenges for future practice. *Down Syndrome Research and Practice*. *2*(1), 19-30 https://doi.org/10.3104/reports.26	Perceptions & performance of 27 people with Down syndrome were examined in performance. QOL between participants was compared to one another, suggesting that training leads to behavioral gains in the community.
3	Brown, R. I., & Timmons, V. (1994). Quality of life – adults and adolescents with disabilities. *Exceptionality Education Canada, 4*(1), 1-11.	
4	Goode, D.A. & Hogg, J. (1994). Towards an understanding of holistic quality of life in people with profound intellectual and multiple disabilities. In D. Goode, D. (ed.), *Quality of life for persons with disabilities. International perspectives and issues* (pp. 197-207). Cambridge: Brookline Books.	
5	Heinlein, K.B. (1994). Quality of care, quality of life: A rural perspective. *Mental Retardation*, *32*, 374-376. https://psycnet.apa.org/record/1995-14781-001	Wyoming's division of DD approaches incorporating fiscal accountability, parental & consumer satisfaction, notational accreditation standards & broad measure of personal & system change.
6	Keith, K. D., & Schalock, R. L. (1994). The measurement of quality of life in adolescence: The quality of student life questionnaire [QLSQ]. *The American Journal of Family Therapy*, *22*(1), 83-87 https://doi.org/10.1080/01926189408251300	The 40-item QLSQ was field tested with 400 junior high & senior high school students in two Nebraska schools. The QLSQ with 4-factors (satisfaction, well-being, social belonging, empowerment/ control) was reported to be a brief and reliable tool that could help family therapists to understand perceptions of adolescents within families.
7	Norton, P., & Drew, C. (1994). Autism and potential family stressors. *The American Journal of Family Therapy, 22*(1), 67-76 https://doi.org/10.1080/01926189408251298	The effects & problem areas of a family member with autism (communication, bonding, early sleep patterns, unpredictable behavior, difficulties created by changes in routine, splinter effects, respite, & finances) was examined, as each area is an important insight for professionals working with these families.
8	Ouellette-Kuntz, H., McCreary, B. D., Minnes, P., & Stanton, B. (1994). Evaluating quality of life: The development of the quality of life interview schedule (QUOLIS). *Journal on Developmental Disabilities, 3*(2), 17-31. https://www.jstor.org/stable/27520846	This study was done to refine the QUOLIS that was designed to measure the QOL of adults with disabilities who are unable to speak for themselves. It was done through 10 interviews with parents & counselors, indicating QUOLIS is an acceptable way of rating QOL.

9	Romney, D.M., Brown, R.I. and Fry, P.S. (Eds), (1994). *Improving the quality of life: Recommendations for people with and without disabilities*. Dordrecht: Kluwer. https://www.amazon.com/Improving-Quality-Life-Recommendations-Disabilities/dp/0792332342	The book focused on improving QOL in a variety of populations with disabilities with its challenges & controversies on the subject.
10	Rootman, I., Brown, I., Raphael, D., & Renwick, R. (1994). How is quality of life related to health and health promotion? In P.-E. Liss & N. Nikku (Eds.), *Health promotion and prevention: Theoretical and ethical aspects* (pp.31-42). City and country: Swedish Council for Planning and Coordination of Research. https://link.springer.com/article/10.1007/BF00300833	This study examined six methods of evaluating QOL & health, including HRQOL, QOL as a social diagnosis in health promotion, QOL among persons with DD, & QOL as social indicators, the Centre for Health Promotion (University of Toronto) model, & Lindstrom's QOL model.
11	Schalock, R. L. (1994). Quality of life, quality enhancement, and quality assurance: Implications for program planning and evaluation in the field of mental retardation and developmental disabilities. *Evaluation and Program Planning*, *17*(2), 121-131. https://doi.org/10.1016/0149-7189(94)90049-3	This paper discusses the concepts of QOL, quality enhancement, & quality assurance as they relate to ID, DD, & potential implications.
12	Schalock, R.L. (1994). The concept of quality of life and its current applications in the field of mental retardation/ developmental disabilities. In D.A. Goode (Ed.), *Quality of Life for Persons with Disabilities: International Perspectives and Issues* (pp. 266-284). Cambridge: Brookline Books.	
13	Wehmeyer, M.L. (1994). Employment status and perceptions of control of adults with cognitive and developmental disabilities. *Research in Developmental Disabilities*, *15*(2), 119-131. https://doi.org/10.1016/0891-4222(94)90017-5	Examination of the relationship between individual perceptions of control & employment status among 200 adults with IDD indicated that there remains a need to focus more on including choice & control into IDD- related interventions.
14	Woodill, G., Renwick, R., Brown, I., & Raphael, D. (1994). Being, belonging, becoming: An approach to quality of life of persons with developmental disabilities. In D. Goode (Ed.). *Quality of life for Persons with Disabilities: International Issues and Perspectives*. New York: Brookline Press.	

	1995	**Summary of Work**
1	Brown, R. I. (1995) Measuring new dimensions through quality of life. *Evaluation Journal of Australia*. *7*(1), 14-23.	
2	Brown R. I. (1995, September). The family and the profession: Issues of quality of life for the consumer. *The School Counsellor Queensland*. Reprinted from Keynote address 5th National Conference of the Australian Guidance and Counselling Association.	
3	Chubon, R. A., Clayton, K. S., & Vandergriff, D. V. (1995). An exploratory study comparing the quality of life of South Carolinians with mental retardation and spinal cord injury. *Rehabilitation Counseling Bulletin*, *39*(2), 107-118. https://eric.ed.gov/?id=EJ525636	A comparison of QOL (measured by The Life Situation Survey) of 100 adults with spinal cord injury & 120 adults with mental retardation indicated that the latter experienced a lower QOL.
4	Felce, D. & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, *16*(1), 51-74. https://doi.org/10.1016/0891-4222(94)00028-8	Description of a multidimensional QOL model that covered subjective & objective indicators with multiple domains of wellbeing (physical, material, social, emotional, & development & activity) & measurements applicable to both people with & without disabilities.
5	Hughes, C., Hwang, B., Kim, J., & Eisenman, L. T. (1995). Quality of life in applied research: A review and analysis of empirical measures. *American Journal on Mental Retardation, 99*(6), 623-641.	Comprehensive review of 87 studies to assess the QOL of people with disabilities: demographic variables, type of investigation, method of assessment methods, psychometrics of tools, & common dimensions of measurements investigated & frequency of measurement.
6	Keith, K. D., & Schalock, R. L. (1995). *Quality of student life questionnaire [QSLQ]*. Worthington, OH: IDS Publishing. https://psycentre.apps01.yorku.ca/wp/quality-of-student-life-questionnaire-qsl-q/	Book describes use of QSLQ to assess social & educational needs, evaluate program outcomes, & as a dependent measure in research on social & educational issues related to students' QOL.
7	Simon, E. W., Rosen, M., Grossman, E., & Pratowski, E. (1995). The relationships among facial emotion recognition, social skills, and quality of life. *Research in Developmental Disabilities, 16*(5), 383-391. https://doi.org/10.1016/0891-4222(95)00025-I	The Vineland Adaptive Behavior Scale & Facial Emotional test was administered to 46 adults with mild to moderate ID to examine the relationship between facial emotional regulation, QOL, & social skills. Findings indicate a significant difference between emotional regulation among specific emotions.

	1996	**Summary of Work**
1	Browne, G., & Bramston, P. (1996). Quality of life in the families of young people with intellectual disabilities. *Australian & New Zealand Journal of Mental Health Nursing*, *5*(3), 120-130. https://pubmed.ncbi.nlm.nih.gov/9079307/	An investigation used both objective & subjective dimensions & the importance of these dimensions to determine the QOL in 102 families of young people with IDD
2	Brown, I., Renwick, R., & Nagler, M. (1996). The centrality of quality of life in health promotion and rehabilitation. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues, and applications.* Thousand Oaks, CA: Sage Publications. https://psycnet.apa.org/record/1996-97773-000	This book establishes that QOL is linked with health promotion & rehabilitation using key themes & concepts that represent a broad spectrum of disciplines.
3	Campo, S. F., Sharpton, W. R., Thompson, B., & Sexton, D. (1996). Measurement characteristics of the quality of life index when used with adults who have severe mental retardation. *American Journal on Mental Retardation*, *100*(5), 546-550. https://eric.ed.gov/?id=EJ519923	The QOL index was completed by residential staff for 60 adults with severe ID living in group homes & was then compared with results gathered from a more heterogeneous sample.
4	Cunningham, C. (1996). Families of children with Down syndrome. *Down Syndrome Research and Practice*, *4*(3), 87-95. https://library.down-syndrome.org/en-gb/research-practice/04/3/families-down-syndrome/	Longitudinal study examined the factors that influence the well-being of 181 families of children with Down syndrome & found that most families don't display pathology because of having a child with Down syndrome.
5	Keith, K.D., Heal, L.W., Schalock, R.L. (1996). Cross-cultural measurement of critical quality of life concepts. *Journal of Intellectual and Developmental Disability, 21*(4), 273-293. https://doi.org/10.1080/13668259600033201	This study assessed the meaning of 10 QOL concepts across 7 cultures (Australia, England, Finland, Japan, China, Germany, & USA) by asking 203 professionals to rate each of these concepts on 9 pairs of adjectives representing three dimensions (value, potency, or activity). Across the 7 countries all 10 of the QOL concepts received strong positive ratings on the value dimension, and lower positive ratings on the potency and activity dimensions
6	Matikka, L. M. (1996). Effects of psychological factors on the perceived quality of life of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 9*(2), 115-128. https://doi.org/10.1111/j.1468-3148.1996.tb00102.x	The study investigated the relationship between personality traits, disability awareness, resources, personal values, & QOL in 619 people with IDs. Results indicated that happiness was associated with higher self-esteem & self-image, while stress was associated with lower self-esteem & a lack of awareness of disability.
7	Neumayer, R. & Bleasdale, M. (1996). Personal lifestyle preferences of people with an intellectual disability. *Journal of Intellectual and Developmental Disability, 21*(2), 91-114. https://doi.org/10.1080/13668259600033071	3o semi-structured interviews conducted to understand preferences, viewpoints, & values of people with an IDD in four major life areas (home, work, leisure & relationships).
8	Raphael, D., Brown, I., Renwick, R., & Rootman, I. (1996). Assessing the quality of life of persons with developmental disabilities: description of a new model, measuring instruments, and initial Findings. *International Journal of*	This study presented a conceptual model of QOL, associated instrumentation for collecting data from persons with DDs, & provided evidence of the

	Disability, Development, and Education, *43*(l), 25-42. https://doi.org/10.1080/0156655960430103	reliability & validity of the model through results from a preliminary study.
9	Rapley, M. & Beyer, M. (1996). Daily activity, community participation and quality of life in an ordinary housing network. *Journal of Applied Research in Intellectual Disabilities*, *9*(1), 31-39. https://doi.org/10.1111/j.1468-3148.1996.tb00096.x	This article looked at a small-scale study that assessed the extent to which objective measures of service quality were enhanced by the addition of a subjective, QOL, measure by looking at service users' engagement in domestic activity, staff contacts, & participation in the local community.
10	Renwick, R., & Brown, I. (1996). The centre for health promotion conceptual approach to quality of life: being, belonging, and becoming. In R., Renwick, I. Brown, & M. Nagler (Eds.), *Quality of Life in Health Promotion and Rehabilitation: Conceptual Approaches, Issues, and Applications.* Thousand Oaks, CA: Sage Publications. https://us.sagepub.com/en-us/nam/quality-of-life-in-health-promotion-and-rehabilitation/book5528	Review of six approaches that consider QOL & health: HQOL, QOL as social diagnosis, QOL among persons with DDs, QOL as social indicators, the Centre for Health Promotion (University of Toronto) model, & Lindstrom's QOL model.
11	Schalock, R.L. (ed.) (1996). *Quality of life, Vol.1. Conceptualization and measurement.* Washington: American Association on Mental Retardation. https://eric.ed.gov/?id=ED404778	The volume of this book focused on the conceptualization & measurement of QOL for persons with mental retardation & DDs.

	1997	**Summary of Work**
1	Brown, R. I. (1997). Quality of life and professional education. In R. I. Brown, (Ed.), *Quality of Life for People with Disabilities: Models, Research and Practice.* Cheltenham. Stanley Thornes.https://books.google.com/books?hl=en	This book chapter focused on the development of QOL models & whether the approaches are utilized within various service systems. To what extent are staff knowledgeable about QOL, & the degree to which this knowledge is expressed.
2	Brown, R. I. (1997). Quality of life: The development of an idea. In R. I. Brown (Ed.)*, Quality of life for people with disabilities: Models, research and practice.* Cheltenham, United Kingdom: Stanley Thornes. https://books.google.com/books?hl=en&lr=&id=	This book chapter focused on how the field of QOL has changed drastically & grown within scientific & disability fields as well as political & social policy domains & is now often seen as a holistic phenomenon.
3	Butterworth, J., Steere, D.E. & Whitney-Thomas, J. (1997). Using person-centered planning to address personal quality of life. In R.L. Schalock (Ed.), *Quality of life, vol. II. Applications to persons with disabilities* (5-23). Washington: American Association on Mental Retardation. https://books.google.com/books?hl=en&	This volume summarized current policies & practices that influence persons with disabilities in three parts: service delivery applications, organizational change applications, & discussion of more relevant public policy.
4	Campo, S.F., Sharpton, W.R., Thompson, B. & Sexton, D. (1997). Correlates of the quality of life of adults with severe or profound mental retardation*. Mental Retardation*, *35*(5), 329-337. https://pubmed.ncbi.nlm.nih.gov/9339061/	60 adults with severe disabilities living in community-based homes surveyed using the QOL Index, to examine interrelations among personal lifestyle characteristics of adults & community-home program characteristics with QOL factors.
5	Cummins, R.A. (1997). Assessing quality of life. In R.I. Brown (Ed.)*, Assessing quality of life for people with disabilities: Models, research, and practice* (pp. 16-150). London: Stanley Thomes. https://books.google.com/books?	This book chapter focused on examining the QOL assessment issues for people with & without a disability using contemporary theoretical & empirical studies
6	Cummins, R.A. (1997). Self-rated quality of life scales for people with an intellectual disability: A review. *Journal of Applied Research in Intellectual Disabilities. 10*(3), 199-216. https://doi.org/10.1111/j.1468-3148.1997.tb00017.x	This article examined 13 QOL scales & found that the two most promising scales were the QOL Questionnaire & the Comprehensive QOL Scale. However, both require further development to maintain their relevance.
7	Cummins, R. A., McCabe, M. P., Romeo, Y., Reid, S., & Waters, L. (1997). An initial evaluation of the comprehensive QOL scale--intellectual disability. *International Journal of Disability*, *Development and Education*, *44*(1), 7-19. https://doi.org/10.1080/0156655970440102	This article describes the Comprehensive QOL Scale that measures both objective & subjective data, using simple language, across several QOL dimensions.
8	Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, *41*(2), 126-135. https://doi.org/10.1111/j.1365-2788.1997.tb00689.x	This article examined a QOL model which integrated objective & subjective indicators & individual values across a range of life domains that are categorized within six areas: physical, material, social, productive, emotional, & civic well-being.
9	Hogg, J. & Lambed, L. (1997). An ecological perspective on the quality of life of people with intellectual disabilities as they age. In R.I. Brown (Ed.)*, Quality of life for people with disabilities:*	This book chapter focused on how increasing life expectancy influences the QOL of older people with

	Models, research, and practice (2nd ed., pp. 201-227). Cheltenham: Stanley Thornes. https://books.google.com/books?hl	disabilities in terms of their relationships with family, neighbors, friends, & community support
10	Matikka, L.M. & Vesala, H.T. (1997). Acquiescence in quality-of-life interviews with adults who have mental retardation. *Mental Retardation*, *35*(2), 75-82. https://pubmed.ncbi.nlm.nih.gov/9131867/	This study examined 616 people with ID to report when an item-reversal technique was used, 11% to 36% of respondents answered acquiescently. No significant correlations existed between acquiescence & level of ID.
11	Rapley, M. & Beyer, S. (1997). Daily activity, community participation and quality of life in an ordinary housing network: A two-year follow up. *Journal of Applied Research in Intellectual Disabilities*, *10*(4), 259-269. https://doi.org/10.1111/j.1468-3148.1998.tb00032.x	This article reported follow-up data from their 1996 study of a community-based housing service that used the QOL Questionnaire to show evaluative measures of service quality.
12	Rapley, M. & Hopgood, L. (1997). Quality of life in a community-based service in rural Australia. *Journal of Intellectual & Developmental Disabilities, 22*(2), 125-141. https://doi.org/10.1080/13668259700033351	This study examined a community-based service, accommodating 34 people with IDs in Australia & found a significant variation in the quality-of-service provision for domestic participation, little autonomy, & impoverished community membership for individuals with an ID.
13	Romeo, Y., Waters, L., McCabe, M., Cummins, R., & Reid, S. (1997). An initial evaluation of the comprehensive quality of life scale-intellectual disability. *International Journal of Disability, Development and Education, 44*(1), 7-19. https://doi.org/10.1080/0156655970440102	This article described the Comprehensive QOL Scale-ID with comparisons between data collected from 59 people with an ID. This scale was useful to measure comparative life quality.
14	Schalock, R. L. (1997). The concept of quality of life in 21st century disability programmes. In R. I. Brown (Ed.), *Quality of life for people with disabilities: Models, research and practice* (pp. 327-340). London: Chapman & Hall. https://books.google.com/books?hl	Book chapter describes how programs for people with DDs significantly change over time & discusses what 21st century programs might look like & what actions will be needed.
15	Schalock, R. L. (1997). The conceptualization and measurement of quality of life: Current status and future considerations. *Journal on Developmental Disabilities*, *5*(2), 1-21. *Reprinted in Special 20th Anniversary Issue of JODD (2006). https://psycnet.apa.org/record/1998-10562-001	This article integrated work related to the conceptualization & measurement of the QOL concept & concluded with several specific questions & potential answers regarding the concept's conceptualization & measurement.
16	Storey, K. (1997). Quality of life issues in social skills assessment of persons with disabilities. *Education and Training in Mental Retardation and Developmental Disabilities, 32*(3), 197-200. http://www.jstor.org/stable/23879149	QOL issues in social skills assessment of persons with disabilities are reviewed & discussed. It is argued that broader measures need to be used to evaluate QOL changes
17	Vreeke, G., Jansson, C.G., Resnik, S. & Stolk, J. (1997). The quality of life of people with mental retardation: in research of an adequate approach. *International Journal of Rehabilitation Research*, *20*, 289-301. https://doi.org/10.1097/00004356-199709000-00005	This article examined a new instrument being developed that measures QOL by an adequate definition of QOL, as it relates to people with mental retardation.

	1998	**Summary of Work**
1	Brown, R. I. (1998). Personal reflections: Quality of life research and Down Syndrome. *International Journal of Disability, Development and Education*. *45*(3), 323-329. https://doi.org/10.1080/1034912980450307	This paper illustrated changes in research development using QOL Model for those with Down syndrome. QOL studies impact aims, direction, structure, & interpretation of research influencing the progress of individuals.
2	Brown, R. I. (1998). The effects of quality-of-life models on the development of research and practice in the field of Down Syndrome. *Down Syndrome Research and Practice*. *5*(1), 39-42. https://doi.org/10.3104/reviews.74	Summarizes research developments in relation to the QOL model in ID, including QOL measures, perceptual measures, experimental vs. other types of research, & implications for future research applied to individuals with Down syndrome.
3	Brown, I., Raphael, D. & Renwick, R. (1998). *Quality of life instrument package for adults with developmental disabilities, full version: Manual and instruments*. Toronto, ON, Canada: Centre for Health Promotion, University of Toronto. http://sites.utoronto.ca/qol/projects/adults.htm	This book describes the QOL Profile, which was made to provide a measure that considers both the components & determinants of health & well-being.
4	Dagnan, D., Ruddick, L., & Jones, J. (1998). A longitudinal study of the quality of life of older people with intellectual disability after leaving hospital. *Journal of Intellectual Disability Research*, *42*(2), 112-121. https://doi.org/10.1046/j.1365-2788.1998.00108.x	A longitudinal study using the cut version of Questionnaire on QOL administered to 29 older people with ID, indicated improvement in QOL in the first 41 months (~ 3.5 years) with eventual leveling out after 53 months (4.5 years). There was a significant increase in community leisure activities from 30 months (~ 2.5 years) to 41 months (3.5 years) after leaving the hospital.
5	Hatton, C. (1998). Whose quality of life is it anyway? Some problems with the emerging quality of life consensus. *Mental Retardation, 36*(2), 104-115. https://pubmed.ncbi.nlm.nih.gov/9573720/	A critique of an emerging QOL consensus suggested problems in measuring subjective indicators & flaws to the QOL approach. Need to explore other approaches.
6	McVilly, K., & Rawlinson, R. B. (1998). Quality of life issues in the development and evaluation of services for people with intellectual disability. *Journal of Intellectual and Developmental Disability, 23*(3), 199-218. https://doi.org/10.1080/13668259800033701	A review of objective & subjective QOL components with process-centered & outcome-centered approaches was evaluated, emphasizing future research is needed in QOL evaluations between people who have ID & their proxies.
7	Ridgway, J., & Rapley, M. (1998). Quality of life talk and the corporatization of intellectual disability. *Disability & Society*, *13*(3), 451-471. https://doi.org/10.1080/09687599826740	The article offers an alternative analytic perspective on influencing the shift away from institutional services to promote service quality measures used by government & psych complex in United Kingdom.
8	Wehmeyer, M. & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, *33*(1), 3-12. https://eric.ed.gov/?id=EJ577358	Discriminant function analysis & correlational analysis on 50 individuals with ID indicated that there was a direct relationship between QOL & self-determination, emphasizing the need to promote self-determination of people with IDD.

	1999	**Summary of Work**
1	Ager, A., & Hatton, C. (1999). Discerning the appropriate role and status of 'quality of life' assessment for persons with intellectual disability: A reply to Cummins. *Journal of Applied Research in Intellectual Disabilities, 12*(4), 335-339. https://doi.org/10.1111/j.1468-3148.1999.tb00089.x	A review of Cummin's analysis of pre-existing measures of QOL indicated a more complex relationship between objective & subjective measures of life experiences & a more empowering role of QOL measurements for service providers than it is for service users with ID.
2	Brown, I. (1999). Embracing quality of life in times of spending restraint. *Journal of Intellectual and Developmental Disability, 24*(4), 299-308. https://doi.org/10.1080/13668259900034061	A paper reframed QOL in times of spending restraint ensuring adequate service standards that are beneficial for those with ID, offering three broad goals with application to use resources to help people live better.
3	Brown, I. (1999). Setting the foundation for a quality of life model in exceptional education [Editorial]. *Exceptionality Education Canada,* 9(2), 57-59.	
4	Brown, I. (1999). Special theme issue: Inclusion & quality of life. *Exceptionality Education Canada (International),* 9(2).	
5	Brown, I., Raphael, D., & Renwick R. (1999). Quality of life profile: Children's version. Toronto, ON: Centre for Health Promotion, University of Toronto.	
6	Brown, R. I., & Shearer, J. (1999). Challenges for inclusion within a quality of life model for the 21st century. *Australian Journal of Special Education*, *22,* 16-23. http://doi.org/10.1080/1030011990220306	QOL studies on children with disabilities emphasizing need for inclusion using QOL model with implementation needed for education purposes for inclusion to be effective in family, community, & educational settings.
7	Eggelton, I., Robertson, S., Ryan, J. & Kober, R. (1999). The impact of employment on the quality of life of people with an intellectual disability. *Journal of Vocational Rehabilitation*, *13*, 95 107. https://research.monash.edu/en/publications/the-impact-of-employment-on-the-quality-of-life-of-people-with-an-2	Impact of QOL on employment of those with IDD was seen using data from Edge Employment Solutions. Results showed higher QOL in employed individuals compared to their unemployed counterparts with no significant difference using a sheltered workshop.
8	Janssen, C. G. C., Vreeke, G. J., Resnick, S., & Stolk, J. (1999). Quality of life of people with mental retardation — Residential versus community living. *British Journal of Developmental Disabilities, 45*(88), 3-15. https://doi.org/10.1179/096979599799156019	A four-dimensional model used to compare QOL of individuals with mild to moderate ID living in residential care facilities (n = 80) with those living in the community (n = 119). Results showed significantly better QOL for those who live in community group homes.
9	Matthews, B., Brown, R. I., & Taylor, J. (1999). Quality of Life — Ageing and Down syndrome. *Down Syndrome: Research and Practice*. *6*(3), 111-118. https://doi.org/10.3104/case-studies.101	Pilot qualitative research study that examined the QOL and views on ageing of seven older adults (45-70 years) with Down syndrome using the Brown & Bayer Rehabilitation Questionnaire: *A Personal Guide to the Individual's Quality of Life*. There is a need to recognize the principles of variability, perception, and choice, while providing support to encourage dignified and active lifestyles.

10	Raphael, D., Steimnetz, B., Philips., S., Sehdev, H., Renwick, R., Brown, I., Smith, T., & Rootman, I. (1999). The community quality of life project: A health promotion approach to understanding communities. *Health Promotion International, 14*(3), 197-210. https://doi.org/10.1093/heapro/14.3.197	This article analyzed an approach that considers community QOL & draws upon recent developments in health promotion & QOL & applies these concepts within a community-based health promotion framework to identify themes.
11	Schalock, R. L. (1999). A quest for quality: Achieving organizational outputs and personal outcomes. A national perspective. In J. F. Gardner & S. Nudler (Eds.), *Quality performance*.	
12	Schalock, R. L. (1999). The promises and challenges of the concept of quality of life. *Exceptionality Education Canada, 9*(1), 61-82.	
13	Schalock, R. L., DeVries, D. & Lebsack, J. (1999). Enhancing the quality of life. In: S.S. Herr and G. Weber (Eds.), *Aging, Rights and Quality of Life: Prospects for Older Persons with Developmental Disabilities* (81-92). Baltimore: Brookes.	
14	Stancliffe, R. J. (1999). Proxy respondents and the reliability of the quality of life questionnaire empowerment factor. *Journal of Intellectual Disability Research*, *43*(3), 185-193. https://doi.org/10.1046/j.1365-2788.1999.00194.x	Consumer self-reports & proxy responses of 63 adults with ID examined to conclude that QOL-Q empowerment factor is reliable with discrepancies between individual consumers & staff.
15	Symons, F. J., Koppekin, A., & Wehby, J. H. (1999). Treatment of self-injurious behavior and quality of life for persons with mental retardation. *Mental retardation, 37*(4), 297-307. https://pubmed.ncbi.nlm.nih.gov/10463024/	Despite numerous reports documenting changes in self-injurious behaviors, little is known on how these changes relate to systematic QOL improvements. A review of 41 journals, 138 research articles with 436 participants indicated that 40 (29%) articles contained some QOL measures. Limited information was found about nature of change in lifestyle based on immediate changes in self-injurious behaviors.
16	Van Riper, M. (1999). Maternal perceptions of family–provider relationships and well-being in families of children with Down syndrome. *Research in Nursing & Health*, *22*(5), 357-368. https://doi.org/10.1002/(SICI)1098-240X(199910)22:5<357::AID-NUR2>3.0.CO;2-Q	Relationship between family & health care providers were examined using survey data (FAMPRO) from 89 mothers of a child with Down syndrome. When mothers believe that their family's relationship with health care providers is positive & family-centered, they feel more satisfied with the care that their child is receiving & they are more likely to seek help from health care providers. Higher levels of individual & family well-being reported by mothers who (a) want and believe they have, positive family-centered relationships with providers, & (b) feel more satisfied with care received.
17	Verri, A., Cummins, R. A., Petito, F., Vallero, E., Monteath, S., Gerosa, E., & Nappi, G. (1999). An Italian–Australian comparison of quality of life among people with intellectual disability living in the community. *Journal of Intellectual Disability Research, 43*(6), 513-522. https://doi.org/10.1046/j.1365-2788.1999.00241.x	A multivariable analysis with data from Australia & Italy concluded that the scores from 276 individuals with ID & those 192 without an ID had comparable QOL using the Comprehensive QOL scale. Both groups had lower QOL on the domains of material well-being, health, productivity, & community.

18	Wehmeyer, M.L. & Bolding, N. (1999). Self-determination across living and working environments: A matched sample study of adults with mental retardation. *Mental Retardation, 37*(5), 353-363. https://pubmed.ncbi.nlm.nih.gov/10581921/	The type of residence & working environment among adults with ID were analyzed. Results indicated that self-determination, autonomy, satisfaction, & opportunities for choice making differed among the type of setting.

	2000	**Summary of Work**
1	Brown, R. I. (2000). Quality of Life: An opportunity to reorganize services within a person-centered approach to disability. *Australian Journal of Rehabilitation Counselling*. https://doi.org/10.1017/S1323892200000971	This paper examined QOL features & principles and presents the QOL concept with its implications on research, policy, & management practices.
2	Cooper, B., & Picton, C. (2000). The long-term effects of relocation on people with an intellectual disability: Quality of life, behavior, and environment. *Research on Social Work Practice. Special*, *10*(2), 195-208. https://doi.org/10.1177/104973150001000203	This article reported long-term effects of relocation from an institution to the community based on the experiences of 45 people with an ID. Results revealed that a move to supportive community residences was associated with increased QOL.
3	Keith, K. D., & Schalock, R.L. (2000). Cross-cultural perspectives on quality of life. *Washington, DC: American Association on Mental Retardation.* *Translated into Japanese (2002; JAIDD). https://www.kul.pl/files/1212/gfx/nowy_folder/	This article summarized differences in QOL among individuals with disabilities living in the open community, compared to 57 who lived in institutions. The QOL Questionnaire found that individuals with ID living in the community had a higher QOL.
4	McVilly, K.R., Burton-Smith, R.M. & Davidson, J.A. (2000). Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities. *Journal of Intellectual & Developmental Disability, 25(1)*, 19-39. https://doi.org/10.1080/132697800112767	This article examined concurrence between self-reported QOL & assessments of QOL made by proxies through two studies, using ComQol-A4 (N = 78) & ComQol-ID4 (N = 24) to find that both studies indicated a high degree of subject/proxy concurrence.
5	Neilson, A., Hogg, J., Malek, M., & Rowley, D. (2000). Impact of surgical and orthotic intervention on the quality of life of people with profound intellectual and multiple disabilities and their careers. *Journal of Applied Research in Intellectual Disabilities*, *13*(4), 216-238. https://doi.org/10.1046/j.1360-2322.2000.00023.x	This study considered the impact of surgical & orthotic interventions on the QOL of 27 people with PIMDs using a pre–post-test basis with respect to: economic costs of interventions, clinical assessment of function & behavior, the participants' QOL, & career satisfaction.
6	Persson, B. (2000). Brief Report: A longitudinal study of quality of life and independence among adult men with Autism. *Journal of Autism and Developmental Disorders, 30*(1), 61-66. https://doi.org/10.1023/A:1005464128544	This longitudinal study explored the benefits of the TEACCH Structured Teaching model on the independence, skills, & QOL of adults with autism. Progression of skills was significant & functional QOL increased for the seven study participants.
7	Schalock, R.L. (2000). Three decades of quality of life. *Focus on Autism & Other Developmental Disabilities*, *15*(2), 116-127. https://doi.org/10.1177/108835760001500207	This article reviewed the current understanding of the QOL construct by examining previous efforts at defining the concept & examining issues that will likely affect this construct in the future.

	2001	**Summary of Work**
1	Alderson, P. (2001). Downs Syndrome: Cost, quality and value of life. *Social Science & Medicine, 53*(5), 627-638. https://doi.org/10.1016/S0277-9536(00)00365-8	This paper conducted qualitative research with 40 adults with congenital conditions & interviewed 5 adults with Down syndrome to find the need for more social research with people who have congenital conditions.
2	Borthwick-Duffy, S. A. (2000). Quality of life and quality of care in mental retardation. In *Mental Retardation in the Year 2000* (pp. 52-66). New York, NY: Springer New York.	This chapter presents a review of early work in QOL of people with ID, summarizes the state of knowledge, and suggests issues that are likely to be the focus of study in the 21st century.
3	Brown, R., Taylor, J., & Matthews, B. (2001). Quality of life - ageing and Down syndrome. *Down Syndrome Research and Practice, 6*(3), 111-116. https://doi.org/10.3104/case-studies.101	This article used qualitative research to examine QOL of 45-70 year old adults with Down syndrome. Authors reported on the life experiences & interests of seven adults & their perceptions concerning their past & present, & the ageing process.
4	Cummins, R. A. (2001). Living with support in the community: Predictors of satisfaction with life. *Mental Retardation and Developmental Disabilities Research Reviews, 7(2),* 99-104. https://doi.org/10.1002/mrdd.1014	This article examined the determinants of life satisfaction of people with an ID & suggested that life satisfaction is under considerable endogenous control & does not normally vary in sympathy with changes in the external environment.
5	Cummins, R. A. (2001). Self-rated quality of life scales for people with an intellectual disability: A reply to Ager & Hatton. *Journal of Applied Research in Intellectual Disabilities, 14*(1), 1-11. https://doi.org/10.1111/j.1468-3148.1997.tb00017.x	The paper addressed the issues raised in an earlier publication that uses a reappraisal of the Life Experiences Checklist to confirm that this instrument is not adequate to measure QOL in accordance with the current understanding of the construct.
6	Gregory, N., Robertson, J., Kessissoglou, S., Emerson, E., & Hatton, C. (2001). Factors associated with expressed satisfaction among people with intellectual disability receiving residential supports. *Journal of Intellectual Disability Research: JIDR*, *45*(Pt 4), 279–291. https://doi.org/10.1046/j.1365-2788.2001.00324.x	This study used semi-structured interviews to examine the factors associated with variations in the levels of satisfaction among adults with ID receiving residential supports (N = 96), living in either a village community, or receiving community-based supports.
7	Grenwald-Mayes, G. (2001). Relationship between current quality of life and family of origin dynamics for college students with attention- deficit/hyperactivity disorder. *Journal of Attention Disorders, 5*(4), 211-222. https://doi.org/10.1177/108705470100500403	This study examined the relationship between QOL, family of origin relationship dynamics, & the presence in 37 students with ADHD. Students with ADHD reported lower QOL but they did not differ in reported family of origin relationship dynamics.
8	Hensel, E. (2001). Is satisfaction a valid concept in the assessment of quality of life of people with intellectual disabilities? A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, *14*(4), 311–326. https://doi.org/10.1046/j.1468-3148.2001.00081.x	This article examined the definitions of QOL, the use of satisfaction as a measure of QOL in people with an ID. The article discussed that there is a compelling argument for the abandonment of measures of QPL in general for people with IDs.
9	Magill-Evans, J., Darrah, J., Pain, K., Adkins, R., & Kratochvil, M. (2001). Are families with adolescents and young adults with	This study compared 90 adolescents with CP & their families to 75 adolescents without physical disabilities

	cerebral palsy the same as other families? *Developmental Medicine & Child Neurology, 43*(7), 466-472. https://pubmed.ncbi.nlm.nih.gov/11463177/	& their families. They found few differences in family functioning, life satisfaction, or perceived social support between the groups.
10	O'Brien, P., Thesing, A., Tuck, B., & Capie, A. (2001). Perceptions of change, advantage and quality of life for people with intellectual disability who left a long stay institution to live in the community. *Journal of Intellectual and Developmental Disability, 26*(1), 67-82. https://doi.org/10.1080/13668250020032778	A community-based agency provided residential, employment & family support services for 61 people with an ID. Nine years later, 54 of the 61 were located & interviewed about the move & overall, reported that it was positive & caused improvements in QOL.
11	Raphael, D., Renwick, R., Brown, I., Steinmetz, B., Sehdev, H., & Phillips, S. (2001). Making the links between community structure and individual well-being. Community quality of life in Riverdale, Toronto, Canada. *Health and Place*, *7*(3), 17-34. https://doi.org/10.1016/S1353-8292(01)00008-9	This article interviewed 102 community members, service providers, & elected representatives in a Toronto community about aspects that affected QOL to better understand the complex relationship between community structures & individual well-being.
12	Sabaz, M., Cairns, D. R., Lawson, J. A., Bleasel, A. F., & Bye, A. M. E. (2001). The health-related quality of life of children with refractory epilepsy: A comparison of those with and without intellectual disability. *Epilepsia*, *42*(5), 621-628. https://doi.org/10.1046/j.1528-1157.2001.25200.x	This study examined 138 parents of children with refractory epilepsy & found that the HRQOL of children with refractory epilepsy is greatly affected, regardless of ID & that the presence of ID in children with epilepsy decreases HRQOL outcomes.
13	Schneider, J., Gurucharri, L., Gutierrez, A., & Gaebler-Spira, D. (2001). Health-related quality of life and functional outcome measures for children with cerebral palsy. *Developmental Medicine and Child Neurology, 43*(9), 601-608. https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1469-8749.2001.tb00242.x	This study examined HRQL in 30 children with CP by comparing scores of the Child Health Questionnaire (CHQ), the Caregiver Questionnaire (CQ) & the Wee-Functional Independence Measure (WeeFIM). Significant correlations were found between CQ & WeeFIM, but no correlation was found between CHQ & CQ.
14	Wehmeyer, M. L., & Schalock, R. (2001). Self-determination and quality of life: Implications for special education services and supports. *Focus on Exceptional Children, 33*(8), 1-16. https://hdl.handle.net/1808/8643	This article focused on promoting self-determination to enhance QOL in special education services & supports by no longer considering curricular & instructional content as separate from the general curriculum.

	2002	**Summary of Work**
1	Ager, A. (2002). 'Quality of life' assessment in critical context. *Journal of Applied Research in Intellectual Disabilities*, *15*(4), 369-376. https://doi.org/10.1046/j.1468-3148.2002.00133.x	This paper argued shifts in the focus of human services reflect societal trends in values & concerns by identifying & examining the core functions of QOL assessments & relating them to underlying qualities reflected in majority of QOL assessments.
2	Bramston, P., Bruggerman, K., & Pretty, G. (2002). Community perspectives and subjective quality of life. I*nternational Journal of Disability, Developmental and Education, 49*(4), 385-397. https://doi.org/10.1080/1034912022000028358	Examination of feelings of belonging associated with QOL indicated that life satisfaction scores of 132 adolescents with an ID correlated with their levels of activity, friends, & support. People with an ID reported lower use of community facilities & lower social belonging.
3	Brantley, A., Huebner, E.S. & Nagle, R.J. (2002). Multidimensional life satisfaction reports of adolescents with mild mental disabilities. *Mental Retardation. 40*(4), 321-329. https://psycnet.apa.org/record/2002-17863-007	The Multidimensional Students' Life Satisfaction Scale was used to compare life satisfaction of 80 high school students with mild mental disabilities with 80 typically achieving students. Students with mild disabilities reported lower satisfaction with their friendships & higher satisfaction with school experiences.
4	Cummins, R. A. (2002). The validity and utility of subjective quality of life: A reply to Hatton & Ager. *Journal of Applied Research in Intellectual Disabilities*, *15*(3), 261-268.https://doi.org/10.1046/j.1468-3148.2002.00123.x	This article is the author's reply to Hatton & Ager that focused on the psychological reality & measurement of QOL for people with an ID & concerns about the usefulness of subjective life quality measurement for service delivery.
5	Cummins, R. A. (2002). Proxy responding for subjective well-being [SWB]: A review. *International Review of Research in Mental Retardation*, *25,* 183-207. https://doi.org/10.1016/S0074-7750(02)80009-X	This article discussed the use of proxy respondent to assess SWB. The process of proxy was flawed & proxy data, relating to the SWB of people with severe disabilities, cannot be regarded as valid under any circumstances.
6	Hatton, C., & Ager, A. (2002). Quality of life measurement and people with intellectual disabilities: A reply to Cummins. *Journal of Applied Research in Intellectual Disabilities*, *15*(3), 254-260.https://doi.org/10.1046/j.1468-3148.2002.00124.x	This article addressed the debate about the utility of measuring subjective well-being in assessing service quality, the validity of QOL as a construct, & the wider context within which QOL assessment takes place.
7	Hensel, E., Rose, J., Kroese, B. S., & Banks-Smith, J. (2002). Subjective judgements of quality of life: A comparison study between people with an intellectual disability and those without a disability. *Journal of Intellectual Disability Research*, *46*(2), 95-107. https://doi.org/10.1046/j.1365-2788.2002.00343.x	Interviews of 31 people with an ID & 31 controls indicated that participants with ID had poorer health & were less satisfied with their health despite receiving more health checks in the past year than controls.
8	Kober, R. & Eggleton, I.R.C. (2002). Factor stability of the Schalock and Keith (1993) Quality of Life Questionnaire. *Mental Retardation, 40*(2), 157-165. https://pubmed.ncbi.nlm.nih.gov/11925270/	The stability of the 4 QOL Questionnaire factors is investigated for reliability across various populations, finding that 3 of 4 factors were found to be stable.

9	Lindsay, W. R. (2002). Community services and quality of life. *Journal of Applied Research in Intellectual Disabilities, 15*(4), 367-368. https://doi.org/10.1046/j.1468-3148.2002.00144.x	This article focused on evidence that shows that deinstitutionalization for adults with IDs has brought significant improvements in many aspects of QOL.
10	Perry, J. & Felce, D, (2002). Subjective and objective quality of life assessment: Responsiveness, response bias, and resident: Proxy concordance. *Mental Retardation*, *40*(6), 445-456. https://meridian.allenpress.com/idd/article-abstract/40/6/445/8369/Subjective-and-Objective-Quality-of-Life	This study used structured interviews with a random sample of 154 adults with ID & found that two-thirds exhibited response bias. There was a significant difference in scores on the Adaptive Behavior Scale between those who exhibited response bias & those who did not.
11	Pretty, G., Rapley, M., & Bramston, P. (2002). Neighborhood and community experience, and the quality of life of rural adolescents with and without an intellectual disability. *Journal of Intellectual and Developmental Disability, 27*(2), 106-116. https://doi.org/10.1080/13668250220135079-5	This study used the Adaptive Behavior Scale to examine awareness & usage of community facilities, perceptions of neighborhood environments, & subjective QOL of 27 adolescents with & without a mild ID. There were no significant differences between those with & without an ID.
12	Reilly, K. O., & Conliffe, C. (2002). Facilitating future planning for ageing adults with intellectual disabilities using a planning tool that incorporates quality of life domains. *Journal of Gerontological Social Work, 37*(3-4), 105-119. https://doi.org/10.1300/J083v37n03_08	This study interviews 31 families of adults with lifelong disabilities about planning for the future, to help families with planning for the future & involving a variety of QOL domains, including health, financial, vocational, social, civil, & residential well-being.
13	Schalock, R.L., Brown, I., Brown, R., Cummins, R.A., Felce, D., Mattika, L., et al. Keith, K.D. & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts*. Mental Retardation*, *40*, 457-470. https://www.researchgate.net/publication/11055507_Conceptualization_Measure	This article examined issues involving the concept of QOL as it relates to persons with IDs and reflects thoughts about the conceptualization, measurement, & application of this widely used concept in the field of IDD.
14	Schalock R. L. & Verdugo M. (2002). *Handbook on quality of life for human service practitioners.* American Association on Mental Retardation, Washington, DC.	This book provides a clear understanding of the QOL concept, its importance & outlines a guide to understand QOL assessment, application, & evaluation.
15	Walsh, P. N. (2002). 3rd Annual conference of EASPD: Looking to a positive future — the best quality of life for ageing people with intellectual disabilities. *Journal of Intellectual Disability Research, 46*(4), 361-363. https://doi.org/10.1046/j.1365-2788.2002.00410.x	This article examines practice, research, & policy discussed at the conference with the European Association of Service Providers for Persons with Disabilities, who help provide care services to 35 million people with disabilities. Need for future research on ageing & ID was clearly stated.

	2003	**Summary of Work**
1	Brown, I., Anand, S., Fung, W. L. A., Isaacs, B., & Baum, N. (2003). Family quality of life: Canadian results from an international study. *Journal of Developmental and Physical Disabilities, 15*, 207-230. https://doi.org/10.1023/A:1024931022773	Preliminary data from Canada used the FQOL survey to gather information on opportunities available, initiative to access opportunities, attainment, & satisfaction of FQOL among 34 parents of children & adults with ID. Conclusion states policies & family-centered supports for families are needed to maintain & improve their health status.
2	Brown, I., & Brown, R. (2003). *Quality of life and disability: An approach for community practitioners.* London: Jessica Kingsley Publishers. https://books.google.com/books?hl=en&	This book discussed past, present & future perspectives of QOL, identification of needs & the provision of supports/services, individual & family perspectives of QOL, & policy & management of QOL.
3	Kraemer, B.R., McIntyre, L.L. & Blacher, J. (2003). Quality of life for young adults with mental retardation during transition. *Mental Retardation*, *41*(4), 250-262. https://pubmed.ncbi.nlm.nih.gov/12862511/	This study used the QOL Questionnaire of 188 young adults with moderate or severe ID. Those who still attended school or had jobs in the community had significantly higher QOL. Family & environmental related variables influenced the satisfaction subscale.
4	Kravetz, S., Katz, S., Alfa-Roller, I., & Yehoshua, S. (2003). Aspects of a theory of mind [TOM] and self-reports of quality of life by persons with mental retardation. *Journal of Developmental and Physical Disabilities, 15*(2), 165-183. https://doi.org/10.1023/A:1022879401484	The cognitive development of a TOM was assessed by 75 adults with mild to moderate levels of ID. Results indicate TOM development negatively affecting acquiescence with no relationship between TOM & reliability of self-reported QOL.
5	Otrebski, W., Northway, R., & Mansell, I. (2003). Social policy and people with intellectual disabilities in Poland: Enhancing quality of life? *Journal of Learning Disabilities*, *7*(4), 363-374. https://doi.org/10.1177/1469004703074004	An article on key social developments & policies in Poland protecting the rights of those with disabilities while not adequately addressing the needs of those with ID otherwise noting a demand in research related to the link between policy development & QOL with the potential to greatly impact people's lives in identifying necessary modifications.
6	Parent, G., & Paré, C. (2003). Analyse des besoins et mesure de la qualité de vie de personnes présentant une surdicécité associée à une déficience intellectuelle (SADI). / Need analysis and measure of quality of life of people suffering of blindness and deafness related to mental retardation. *Revue Francophone De La Déficience Intellectuelle, 14*(1), 5-39.	
7	Park, J., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., Mannan, H., & Wang, M. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research*, *47*(4-5), 367-384. https://doi.org/10.1046/j.1365-2788.2003.00497.x	A study focused on the development of a new tool to measure FQOL based on survey responses of primary caregivers (n = 428) & the other family members (n = 459). They identified 10 domains of QOL with construct indictors that were perceived as incredibly important by family members.
8	Perry, J., & Felce, D. (2003). Quality of life outcomes for people with intellectual disabilities living in staffed community housing services: A stratified random sample of statutory, voluntary and private agency provision. *Journal of Applied Research in*	This study compared sectors in terms of the processes operating within residential services & assessed QOL resident outcomes using a stratified random sample of 47 small-scale community- based residential settings

	Intellectual Disabilities, 16(1), 11-28. https://doi.org/10.1046/j.1468-3148.2003.00127.x	that accommodated 154 people with ID. Results showed that provider agencies did not differ, but objective measures showed differences in the residence life conditions resulting in a need to address services to support the QOL of all people across the ability spectrum.
9	Poston, D., Turnball, A., Park, J., Mannan, H., Marquis, J. & Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation, 41*(5), 313 -328. https://pubmed.ncbi.nlm.nih.gov/12962536/	A qualitative inquiry on FQOL is conceptualized using 187 interviews on families with & without children with a disability. Results found 10 QOL domains, a description of subdomains, indicators, & key points raised by participants.
10	Schwartz, C., & Rabinovitz, S. (2003). Life satisfaction of people with intellectual disability living in community residences: perceptions of the residents, their parents and staff members. *Journal of Intellectual Disability Research*, *47*(2), 75-84. https://doi.org/10.1046/j.1365-2788.2003.00436.x	Life satisfaction of 93 residents living with ID was compared to perceptions of staff & parents using the Life Satisfaction Scale. Results emphasized the importance of both subjective & objective measurements in understanding the QOL of people with ID.

	2004	**Summary of Work**
1	Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or Fragile X syndrome. *American Journal on Mental Retardation, 109*(3), 237-254. https://pubmed.ncbi.nlm.nih.gov/15072518/	The psychological well-being of mothers of a child with Fragile x (n = 22), Down syndrome (n =39) & ASD (n = 174) were observed. Mothers of children with fragile X syndrome displayed lower levels of well-being in comparison to Down syndrome but higher levels than mothers of children with ASD.
2	Bonham, G.S., Basehart, S., Schalock, R.L., Marchand, C.B., Kirchner, N. & Rumenap, J. M. (2004). Consumer based quality of Life assessment: The Maryland Ask Me! Project, *Mental Retardation*, *42*(5), 338-355. https://www.yumpu.com/en/document/view/7408244/consumer-based-quality	The Maryland Ask Me! project assessed consumer perceived QOL of adults with IDD using the development of a model to enhance social inclusion, personal development, & self-determination in 923 participants.
3	Brown, I. & Brown, R. (2004). Concept for beginning study in family quality of life. In: I. Brown, A. Turnbull & R. Turnbull (Eds.). *Families and People with Mental Retardation and Quality of Life: International Perspectives* (pp. 27-47). Washington, DC: American Association on Mental Retardation.	
4	Cummins, R. A. (2004). Issues in the systematic assessment of quality of life. In J.H. Hogg & A. Langa (Eds.), *Approaches to the Assessment of Adults with Intellectual Disabilities: A service, Providers Guide.* London: Blackwell. https://onlinelibrary.wiley.com/doi/abs/10.1002/9780470773697.ch1	This book described the QOL of those living with an ID including issues on instrument construction, test administration, data screening, scales for people with severe & profound ID.
5	Cummins, R. A. (2004). Instruments for assessing quality of life. In J.H. Hogg &` A. Langa (Eds.), *Approaches to the assessment of adults with intellectual disabilities: A service, providers guide.* London: Blackwell. https://onlinelibrary.wiley.com/doi/abs/10.1002/9780470773697.ch9	This book highlighted the instruments used to analyze QOL. Specific topics discussed include a method of scale selection & evaluation criteria.
6	Larson, S.A., Hewitt, A.S. & Lakin, K.C. (2004). Multiperspective analysis of workforce challenges and their effects on consumer and family quality of life. *American Journal on Mental Retardation*, *109*(6), 481-500. https://doi.org/10.1352/0895-8017(2004)109<481:MAOWCA>2.0.CO;2	The impact of direct support professional (DSP) turnover, wages, & vacancy rates examined from data gathered through interviews with 372 adult service recipients, 20 county managers, & surveys of 183 families, 520 service coordinators, 228 direct support professionals, and 184 residential and 82 vocational managers. Results indicated higher DSP turnover was associated with lower wages & support in urban counties.
7	Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, *34*(3), 245-256. https://doi.org/10.1023/B:JADD.0000029547.96610.df	Individual & environmental factors investigated to determine predictors of peer relationships from 235 adolescents & adults with ASD that live at home. Participation in social & recreational activities were predicted by characteristics of the individual with ASD & characteristics of the environment.

8	Poston, D. J., & Turnbull, A. P. (2004). Role of spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Developmental Disabilities*, *39*(2), 95-108. https://eric.ed.gov/?q=physical+development+of+mental+retardation&pg=861&id=EJ754122	This study of 187 family members of children with disabilities described spirituality as an important aspect of their lives with a need to create strategies to promote inclusive religious communities & enhancement of family spiritual well-being.
9	Schalock, R. L. (2004). *Moving from individual to family quality of life as a research topic. Families and people with mental retardation and quality of life: international perspectives*. Washington: American Association on Mental Retardation-AAMR, 322.	
10	Schalock, R. L. (2004). Quality of life and outcomes management. In W. M. Nehring (Ed.), *Core curriculum for nurses and health professionals specializing in developmental disabilities* (pp. 349-360). New York: Jones and Bartlett Publishers.	This book included applications in educational, social, family, health, & employment aspects of care & provision for those with IDs. This book is focused on the research about QOL & how it encompasses several factors.
11	Emerson, E., Hatton, C., Thompson, T., Parmenter, T. (2004). *International Handbook of Applied Research in Intellectual Disabilities.* John Wiley & Sons.	
12	Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, *48,* 203-216. https://doi.org/10.1111/j.1365-2788.2003.00558.x	A summary of the current knowledge of QOL, what we are beginning to understand, & what we do not know about the concept & application of QOL in individuals with ID in the last two decades. It included the importance of QOL construct, indicators, & domains.
13	Sullivan, P., Juszczak, E., Bachlet, A., Thomas, A., Lambert, B., Vernon-Roberts, A., Jenkinson, C. (2004). Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Developmental Medicine & Child Neurology, 46*(12), 796-800. https://pubmed.ncbi.nlm.nih.gov/15581151/	The effects of gastrostomy tube feeding on QOL of Caucasian 57 children with CP were evaluated using Short Form 36 version II. A measurable improvement in mental health, role limitations due to emotional problems, physical & social functioning, & energy/vitality after a gastrostomy feeding tube has been inserted.
14	Topolski, T., Edwards, T., Patrick, D., Varley, P., Way, M., & Buesching, D. (2004). Quality of life of adolescent males with Attention-Deficit Hyperactivity Disorder. *Journal of Attention Disorders, 7*(3), 163-173. https://doi.org/10.1177/108705470400700304	The Youth QOL instrument was used to determine self-perceived QOL in 55 adolescents with ADHD reporting a significantly lower perceived QOL score in comparison to 107 adolescents with no chronic conditions & 52 adolescents with mobility impairments. Interventions incorporated to improve self-esteem & social interactions are necessary for an increase in QOL outcomes.
15	Turnbull, A., Brown, I., & Turnbull, R. (Eds.) (2004). *Families and persons with mental retardation and quality of life: International perspectives*. Washington, DC: American Association on Mental Retardation. https://books.google.com/books?hl=en&lr=&id=	This book highlighted FQOL internationally by first bringing a foundation of an individual's QOL to FQOL. It also detailed policy, research directions, & perspectives about research, programs, & policy.
16	Turnbull, A., Turnbull, R., Poston, D., Beegle, G., Blue-Banning, M., Frankland, C., Summers, J. A. (2004). *Enhancing quality of*	This book summarized an overview on policy, services, & research relates to FQOL in the United States for

	life of families of children and youth with developmental disabilities in the United States. https://kuscholarworks.ku.edu/handle/1808/6265	children & youth with disabilities. It highlighted the Beach Center's research program in 2000. It also included a case study of the Poston family in terms of their FQOL.
17	Turnbull, I. Brown & H. R. Turnbull (Eds.), *Families and people with mental retardation and quality of life: International perspectives* (pp.51-100). Washington: DC: American Association on Mental Retardation. https://books.google.com/books?hl=en&lr=	This book targeted four themes related to QOL: research, family centered programs, policy & family voices.
18	Turnbull, A. P. (2004). President's address 2004: "Wearing two hats": Morphed perspectives on family quality of life. *Mental Retardation*, *42*(5), 389-399. https://kuscholarworks.ku.edu/handle/1808/6060	AAMR President discussed her morphed perspectives influencing her professional career with insights on the next steps into enhancing QOL & an overview of the five domains of FQOL at the presidential address in 2004.
19	Wang, M., Mannan, H., Poston, D., Turnbull, A.P., & Summers, J.A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities*, *29*(2), 144-155. https://doi.org/10.2511/rpsd.29.2.144	Qualitative analysis of 104 respondents using focus groups & interviews identified two themes with respect to parents' perceptions of their advocacy & three themes regarding the impact of parental advocacy on FQOL with implications for practice being significant.
20	Wang, M., Turnbull, A.P., Turnbull, R., Summers, J.A., Little, T.D., Poston, D.J., & Mannan, H. (2004). Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years. *Research and Practice for Persons with Severe Disabilities*, *29*(2), 82-94. https://doi.org/10.2511/rpsd.29.2.82	A study 234 mothers & 130 fathers of children in early childhood programs indicated that severity of disability significantly predicted both parents' FQOL satisfaction (Beach Center FQOLS). While family income predicted mother's FQOL satisfaction ratings, there were no interaction effects between family income, severity of disability, & FQOL satisfaction ratings.

	2005	**Summary of Work**
1	Aznar A. S. & Castanon D. G. (2005). Quality of life from the point of view of Latin American families: A participative research study. *Journal of Intellectual Disability Research 49*, 784–88. https://doi.org/10.1111/j.1365-2788.2005.00752.x	Research study among 180 Latin American families of individuals with ID attributed importance of QOL measures to interpersonal relations & emotional well-being. Article proposes a topological model of QOL with QOL indicators & domains for Latin Americans.
2	Bramston, P., Chipuer, H., & Pretty, G. (2005). Conceptual principles of quality of life: An empirical exploration. *Journal of Intellectual Disability Research*, *49*(10), 728-733. https://doi.org/10.1111/j.1365-2788.2005.00741.x	The Comprehensive QOL Scale used with 80 young adults with ID indicated that their satisfaction with health was significantly higher than intimacy & community involvement in comparison to 120 young adults in the community. Social support was the biggest indicator of life satisfaction across both groups.
3	Brod, M., Perwien, A., Adler, L., Spencer, T., & Johnston, J. (2005). Conceptualization and assessment of quality of life for adults with attention deficit/hyperactivity disorder. *Primary Psychiatry, 12*(6), 58-64. https://psycnet.apa.org/record/2005-07400-017	This study indicated a synergistic interaction between QOL and ADHD symptoms & associated impairments negatively affecting QOL of adults with ADHD. Key QOL domains from the Adult ADHD QOL scale can help professionals develop in treatment plans that address QOL issues.
4	Brown, R. I. and Brown, I. (2005). The application of quality of life. *Journal of Intellectual Disability Research*, *49*(10), 718-727. https://doi.org/10.1111/j.1365-2788.2005.00740.x	Four applications of QOL with people with ID was set up based on criteria by IASSID & SIRG with a need to enhance QOL principles into professional education & training programs, resulting in modifications in services.
5	Caballo, C., Crespo, M., Jenaro, C., Verdugo, M. A., & Martinez, J. L. (2005). Factor structure of the Schalock and Keith Quality of Life Questionnaire (QOL-Q): Validation on Mexican and Spanish samples. *Journal of Intellectual Disability Research*, *49*(10), 773-776. https://doi.org/10.1111/j.1365-2788.2005.00750.x	The QOL Questionnaire administered to 209 Mexican participants with a physical disability & 424 Spanish participants indicated that the reliability & factor structure (exploratory factor analysis) was like the questionnaire's standardized manual.
6	Crane, L. (2005). Quality-of-life assessment for persons with mental retardation. A*ssessment for Effective Intervention*, *30*(4), 41-50. https://doi.org/10.1177/073724770503000406	The description of QOL assessments for persons with ID was discussed including ways to measure QOL & how to fit QOL into a broader context of assessments.
7	Cummins, R. A. (2005). Caregivers as managers of subjective wellbeing [SWB]: A homeostatic perspective*. Journal of Applied Research in Intellectual Disabilities*, *18*(4), 335-344. https://doi.org/10.1111/j.1468-3148.2005.00267.x	The paper proposes that the adequacy of service delivery & caregiving for people with disabilities should be assessed using both the objective and subjective indicators of wellbeing. People who have a disability are more likely than usual to have a fragile homeostatic system because of the additional life challenges imposed by their disability. Caregiver should provide resources & protection against strong threats to homeostasis, to ensure that the person with ID has a normal-range level of SWB.

8	Cummins, R. A. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research*, *49*(10), 699-706. https://doi-org/10.1111/j.1365-2788.2005.00738.x	In reshaping the conceptualization of QOL, a theoretical model is explained, distinguishing causal & indicator variables within the framework of a homeostatic management system. It investigated areas of objective-subjective dichotomy, needs, & core principles.
9	Cummins, R. A. (2005). Issues in the systematic assessment of quality of life. In J. Hogg &. Langa (Eds.), *Assessing adults with Intellectual Disabilities: A service provider's guide* (pp. 9–22). Maiden, MA: BPS Blackwell. .	
10	Cummins, R. A., & Lau, A. L. (2005). *Personal Wellbeing Index: Pre-school*. 3rd Edition.	A manual of the PWIS, including a description, general procedures, & data interpretation of 7 items of satisfaction. Outlining faces that are incredibly sad to happy was used, alongside an 11-point scale Likert response scale designed for measuring the personal wellbeing of pre-school kids.
11	Cummins, R., & Lau, A. (2005). *Personal Wellbeing Index: School Children*. Victoria: Deakin University.	A manual of the PWIS for children including a description, general procedures, & interpretation of 7 items of satisfaction. It answered the global question of "How satisfied are you with your life as a whole?" using a Likert response scale designed for school-aged children & adolescents.
12	De Waele, I., van Loon, J., Van Hove, G., & Schalock, R. L. (2005). Quality of life versus quality of care: Implications for people and programs. *Journal of Policy and Practice in Intellectual Disabilities*, *2*(3-4), 229-239. https://doi.org./10.1111/j.1741-1130.2005.00035.x https://www.researchgate.net/publication/229911380_Quality_of_Life_Versus_Quality_of_Care_Implications_for_People_and_Programs	The difference between QOL and quality of care (QOC) approach to services & support for persons with ID is explained using an example of how one large agency in the Netherlands converted from a QOC to QOL-focused organization and discuss consequences of such a conversion. QOL discourse emphasized independence, productivity, community integration, & satisfaction. Organizations should encourage a transition to a QOL approach using fundamental principles & strategies.
13	Felce, D., & Perry, J. (2005). Qualità della vita: Il problema delle misure oggettive e soggettive. / Quality of life: Issues of objective and subjective measurement. *Giornale Italiano Delle Disabilita*, *5*(1), 3-14.	
14	Grant, T., Huggins, J., Connor, P., & Streissguth, A. (2005). Quality of life and psychosocial profile among young women with fetal alcohol spectrum disorders. *Mental Health Aspects of Developmental Disabilities, 8*(2), 33-39. https://www.researchgate.net/publication/290276356_Quality_of_Life_and_Psy	An observation of psychosocial & three self-reported measures of 11 women with fetal alcohol spectrum disorder indicated poor QOL scores, prominent levels of mental health disorders, & more behavioral problems in comparison to other at-risk populations.
14	Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum	53 parents of children with ASD from Australia surveyed to examine the relationship between ASD characteristics, family functioning, & coping strategies. Results suggested caregivers have healthy

	disorder. *Autism*, *9*(2), 125-137. https://doi.org/10.1177/1362361305051403	self-esteem & lower marital happiness, family cohesion, & family adaptability. There is a need for support programs dedicated to improving the QOL for parents of caregivers.
16	Janssen, C. G. C., Schuengel, C., & Stolk, J. (2005). Perspectives on quality of life of people with intellectual disabilities: The interpretation of discrepancies between clients and caregivers. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment. Care & Rehabilitation, 14*(1), 57-69. http:// doi.org/10.1007/s11136-004-1692-z .	A study on 973 clients from Dutch residential facilities & their caregivers indicated that there was low to moderate agreement between the QOL reported by individuals with ID & their caregivers. Results indicated dissonance or adaptation using a parallel QOL instrument looking at dimensions of different perspectives, domains in life, goals in life, & norms in life.
17	Jenaro, C., Verdugo, M. A., Caballo, C., Balboni, G., Lachapelle, Y., Otrebski, W., & Schalock, R. L. (2005). Cross-cultural study of person-centered quality of life domains and indicators: a replication. *Journal of Intellectual Disability Res*earch, *49*(10), 734-739. https://doi.org/10.1111/j.1365-2788.2005.00742.x	The *Cross-Cultural Survey of QOL* was used to gather data from three respondent groups (consumers, parents, professionals; N = 781) across four European countries (France, Belgium, Italy, Poland) to evaluate the etic (universal) and emic (culture-bound) properties of QOL internationally. Results supported two hypotheses and replicated findings of a large cross-cultural study indicating that the QOL construct has both etic and emic properties.
18	Jokinen, N., & Brown, R. I. (2005). Family quality of life from the perspective of older parents. *Journal of Intellectual Disability Research*, *49*(10) 789-793. https://doi.org/10.1111/j.1365-2788.2005.00753.x	The FQOL of 15 older parents of adult children with an ID aged 40 or over was evaluated qualitatively using the international FQOL survey. Participants reported positive aspects of lifelong caregiving & concerns about health of family members, social lives of their adult child, long-term living arrangements, & role of siblings. Results indicate the need for more tailored ID services that can adapt to age-related changes to better support both individuals with ID & their families.
19	Kyrkou, M. (2005), Health issues and quality of life in women with intellectual disability. *Journal of Intellectual Disability Research, 49*(10), 770-772. https://doi.org/10.1111/j.1365-2788.2005.00749.x	A questionnaire for 24 parents of women with DS or ASD in Australia & New Zealand. Women with DS reported having pain more often than women with ASD, suggesting that women should be compared within their own disability group.
20	Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbois, Y., Keith, K. D., Schalock, R., & Walsh, P. N. (2005). The relationship between quality of life and self-determination: an international study. *Journal of Intellectual Disability Research*, *49*(10), 740-744. https://doi.org/10.1111/j.1365-2788.2005.00743.x	Self-determination & QOL of 182 persons with mild ID living in community settings was assessed using *the QOL Questionnaire* & The Arc's Self-Determination Scale. Results showed self-determination & QOL were significantly correlated, confirming the importance of self-determination to enhance QOL.
21	Marciano, A. R. F., & Scheuer, C. I. (2005). Quality of life in siblings of autistic patients. *Revista Brasileira de Psiqu*iatria, *27*(1), 67-69. https://doi.org/10.1590/s1516-44462005000100015	QOL among 31 siblings of individuals with ASD and 30 siblings of patients with a speech disorder measured using AUQEI, a questionnaire measuring QOL

		subjectivity. Findings showed that QOL was lower for siblings of individuals with ASD.
22	McCarron, M., Gill, M., McCallion, P., & Begley, C. (2005). Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia. *Journal of Intellectual Disability Research*, *49*(7), 560-566. https://doi.org/10.1111/j.1365-2788.2005.00704.x	This study investigated physical & mental health comorbidities of people (>35 years) with DS with & without AD, indicating that people with AD had significantly greater comorbidity scores than those without AD. There was a significant difference in summed co-morbidity scores for people at end-stage AD vs. those at mid-stage AD, but there were no differences by level of ID.
23	Ones, K., Yilmaz, E., Cetinkaya, B., & Caglar, N. (2005). Assessment of the Quality of Life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabilitation and Neural Repair, 19*(3), 232-237. https://doi.org/10.1177/1545968305278857	A prospective case control study on QOL & psychological status in mothers of children with CP (n = 46) & mothers of healthy children (n = 46) reports BDI scores that were poorer in the MCCP group compared to those in the control group. Results indicated a significantly worse QOL in MCCP with data from Nottingham Health Profile-1, Beck Depression Inventory, & Beck Anxiety Inventory.
24	Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, *18*(1), 35-46. https://doi.org/10.1111/j.1468-3148.2004.00209.x	Parents & direct support staff of people who have profound multiple disabilities (N = 76) were interviewed. Results showed five domains identified by more than half of respondents as being salient for the QOL of people with profound multiple disabilities.
25	Schalock, R. L. (2005). Introduction and overview. *Journal of Intellectual Disability Research, 49*(10), 695-698. https://doi.org/10.1111/j.1365-2788.2005.00737.x	Articles in this 2-part special issue described the QOL construct with articles focusing on conceptualization, measurement & application of the QOL construct, current research, and application efforts.
26	Schalock, R.L., Verdugo, M.A., Jenaro, C., Wang, M., Wehmeyer, M., Jiancheng, X. & Lachapelle, Y. (2005). Cross-cultural study of quality of life indicators. *American Journal on Mental Retardation, 110*(4), 298-311. https://pubmed.ncbi.nlm.nih.gov/15941366/	Surveying three respondent groups on the importance of 24 core QOL indicators resulted in significant differences in mean QOL importance. The survey used scores for both respondent & geographic groupings with factors on importance & generally grouped 8 core QOL domains.
27	Sheppard-Jones, K., Prout, H.T. & Kleinert, H. (2005). Quality of life dimensions for adults with developmental disabilities: A comparative study. *Mental Retardation*, *43*(4), 281-291. https://psycnet.apa.org/record/2005-09096-004	QOL differences existed between adults with DD & the general population indicating those with DD have a lower QOL showing differences in scales by measuring well-being, decision making, & other variables.
28	Shu, B. C., & Lung, F. W. (2005). The effect of support groups on the mental health and quality of life for mothers with autistic children. *Journal of Intellectual Disability Research, 49*(1), 47-53. https://doi.org/10.1111/j.1365-2788.2005.00661.x	A quasi-experimental pre-post control design of 27 mothers with children with ASD included eight participants using a 10-week support group program and 19 participants as a control group. Outcomes measured using the Chinese Health Questionnaire-30 & *WHOQOL-BREF Taiwan version*. Results indicated that mental health had not significantly improved in

		study group compared to controls, while subjective well-being had an impact on their QOL.
29	Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman. L., Wang, M., et al. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research, 49,* 777–83. https://doi.org/10.1111/j.1365-2788.2005.00751.x	An introduction to the Beach Center FQOLS evaluates family ratings of importance & satisfaction of five domains shown to be a valid device for assessing the services on families with future implications for research & practice.
30	Verdugo, M. A., Córdoba, L., & Gómez, J. (2005). Spanish adaptation and validation of the Family Quality of Life Survey. *Journal of Intellectual Disability Research*, *49*(10), 794–798. https://doi.org/10.1111/j.1365-2788.2005.00754.x	An examination of the reliability and validity of FQOL Survey among 385 Spanish families with a child who has a disability indicated adequate temporal stability and excellent internal consistency.
31	Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research*, *49*(10), 707-717. https://doi.org/10.1111/j.1365-2788.2005.00739.x	Important principles & guidelines regarding QOL measurements were discussed with the use of the QOL construct including principles that should guide the measurement process, the major interrogatories of QOL of measurement, issues & procedures in the cross-cultural measurement of QOL, & the current uses of QOL data.
32	Waters, E., Maher, E., Salmon, L., Reddihough, D., & Boyd, R. (2005). Development of a condition-specific measure of quality of life for children with cerebral palsy: Empirical thematic data reported by parents and children. *Child: Care, Health and Development, 31*(2), 127-135. https://doi.org/10.1111/j.1365-2214.2004.00476.x	Qualitative study using grounded theory in a semi-structured interview identified 13 themes of QOL for 28 children with CP & their parents to guide their decision for the new condition specific QOL scale; this aids in clinical interventions & community management.
33	White-Koning, M., Arnaud, C., Bourdet-Loubère, S., Bazex, H., Colver, A., & Grandjean, H. (2005). Subjective quality of life in children with intellectual impairment - how can it be assessed? *Developmental Medicine & Child Neurology*, *47*(4), 281–285. https://doi.org/10.1017/S0012162205000526	A review of the literature on conceptual & methodological issues pertaining to QOL of children with CP & IDD emphasizes that subjective assessments supplied valuable feedback that should be actively consulted regarding their internal state. Both objective & subjective assessments should be comprehensible for the child & based on the child's own interests & life values.

	2006	**Summary of Work**
1	Allik, H., Larsson, J. O., & Smedje, H. (2006). Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. *Health and Quality of Life Outcomes*, *4*(1), 1-8. https://doi.org/10.1186/1477-7525-4-1	Families with a child who has AS/HFA compared the HRQOL & behavioral characteristics to a gender matched child with typical development, showing that mothers with children of AS/HFA have poorer physical health than the control group that may be related to maternal health behavioral problems in the child.
2	Bertelli, M., & Brown, I. (2006). Quality of life for people with intellectual disabilities. *Current Opinion in Psychiatry*, *19*(5), 508-513. http://doil.org/10.1097/01.YCO.0000238479.81528.9F	Both qualitative & quantitative variables from both objective & subjective positions should be measured using a comprehensive system involving both auto & hetero variables with current instruments being vastly different. Care procedures, studies of daily practice, & resources need to be reevaluated & expanded.
3	Brod, M., Johnston, J., Able, S., & Swindle, R. (2006). Validation of the adult attention-deficit/hyperactivity disorder quality-of-life scale (AAQoL): A disease-specific Quality-of-Life Measure. *Quality of Life Research, 15*(1), 117-129. http://doi.org/10.1007/s11136-005-8325-z	A retrospective cohort study of 989 with ADHD indicated that the AAQOL has a robust scale structure with 4 domains that supports a valid construct for measuring QOL with adequate internal consistency.
4	Brown, I., Brown, R. I., Baum, N. T., Isaacs, B. J., Myerscough, T., Wang, M., Neikrug, S., Roth, D., Shearer, J. (2006). *Family quality of life survey: Main caregivers of people with intellectual disabilities*. Toronto, ON: Surrey Place Center. http://www.surreyplace.ca/documents/FQLS%20Files/FQOL-Survey-ID-DD-With-Variable-Names-May-08.pdf	This is an in-detail paper on the FQOL Survey, which gives examples & key definitions about the survey.
5	Brown, R. I, MacAdam-Crisp, J., Iarocci, G.,Wang, M. (2006). Family quality of life when there is a child with a developmental disability*. Journal of Policy and Practice in Intellectual Disabilities, 3*(4), 238-246. https://doi.org/10.1111/j.1741-1130.2006.00085.x	Comparative study on the FQOL in those with a child with ASD (n = 18), a child with Down syndrome (n = 33), and a child without a disability (n = 18) using the international FQOL survey to analyze both qualitative & quantitative information. Families without a child with a disability had statistically higher levels of satisfaction.
6	Colver, A., & SPARCLE group. (2006). Study protocol: SPARCLE – a multi-centre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. *BMC Public Health, 6*(1). http://doi.org/10.1186/1471-2458-6-105	A cross-sectional study examined the relationship between participation & QOL to impairment & environment in children with CP to understand why there are variations between children with impairments. Measurements used are KIDSCREEN, Life-H, Strength & Difficulties Questionnaire, & Parenting Stress Index measurements.
7	Cummins, R. A., & Lau, A. L. D. (2006). *Using health and subjective wellbeing for quality of life measurement: A review.* In L. Bauld, K. Clarke, & T. Maltby (Eds.), Social Policy Review, 18, 165-192. Bristol: Policy Press.	This book provided an opinion on quality adjusted life years & HRQOL. It also connected mental health & QOL within medicine as it evolved. It also displayed the relevance of SWB.

	https://bristoluniversitypressdigital.com/display/book/9781847429186/ch009.xml	
8	Endermann, M. (2006). Quality of life among people with epilepsy and mild intellectual disabilities in residential care. *Epilepsy & Behavior*, *8*(4), 703-712. https://doi.org/10.1016/j.yebeh.2006.02.009	Interviews with 111 people with epilepsy & mild ID in residential care to assess their QOL (generic & CP specific), life satisfaction, Brief Symptom Inventory (BSI), activities of daily life & work-related problems. Weak correlation of generic QOL with epilepsy related QOL, BSI scores on emotional state most influential predictor of QOL.
9	Faragher, R., & Brown, R. I. (2006). Numeracy for adults with Down syndrome: It's a matter of quality of life. *Journal of Intellectual Disability Research*. *49*(10), 761-765. https://doi.org/10.1111/j.1365-2788.2005.00747.x	Using a case study methodology, five adults were observed in two contexts. Results indicated that the numerary development for adults with Down syndrome is linked to the principles of personal contexts, variability, life-span perspective, values, choices & personal control, perceptions, & self-image.
10	Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research*, *50*(12), 970-976. https://doi.org/10.1111/j.1365-2788.2006.00933.x	A longitudinal study on 28 parents coping with ASD over a decade using in-depth interviews & participant observation resulted in a change in coping mechanisms over time with fewer parents coping with service providers, family support, social withdrawal & individualism. More parents coped using religious faith & other emotional support strategies.
11	Hoffman, L., Marquis, J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Beach Center Family Quality of Life Scale. *Journal of Marriage and Family*, *68*(4), 1069-1083. https://doi.org/10.1111/j.1741-3737.2006.00314.x	488 families of children with disabilities were assessed using the Beach Center FQOLS. Confirmatory factor analysis indicated that the scale comprises 25 items that assess 5 FQOL domains of FQOL based on data from two studies. The scale was found to be unidimensional & internally consistent.
12	Jokinen, N. S. (2006). Family quality of life and older families. *Journal of Policy and Practice in Intellectual Disabilities, 3,* 246–252. https://doi.org/10.1111/j.1741-1130.2006.00086.x	Circumstances of older families of adults with ID discussed using current research, practicing literature pertaining to older families, & the basic tenets of FQOL with the potential to identify proactive strategies to expand evidence-based practice & future planning.
13	Lemétayer, F., & Gueffier, M. (2006). Évaluation de la qualité de vie desenfants et des adolescents avec une déficience intellectuelle pris en charge dans un institut spécialisé./ Assessing quality of life of children and adolescents with an intellectual deficiency dealt in a specialized institute. *Revue Francophone De La Déficience Intellectuelle*, *17*, 65-77. https://rfdi.org/wp-content/uploads/2013/05/LEMETAYER_v17.pdf	

14	Maes, B., & Petry, K. (2006). Kwaliteit van leven bij personen met verstandelijke beperkingen./ Quality of life in persons with intellectual disabilities. *Gedrag & Gezondheid: Tijdschrift Voor Psychologie En Gezondheid*, *34*(4), 280-295. https://link.springer.com/article/10.1007/BF03071136	This article critically reviewed assessment tools for measuring QOL in persons with ID, while also analyzing the assorted reasons, at the level of the individual, services & care programs, & the community, for measuring QOL in individuals with ID.
15	Nota, L., Soresi, S., & Perry, J. (2006). Quality of life in adults with an intellectual disability: The evaluation of quality of life instrument. *Journal of Intellectual Disability Research*, *50*(5), 371-385. https://doi.org/10.1111/j.1365-2788.2006.00785.x	The *Evaluation of QOL Instrument* (EQLI) designed to elicit information from staff of health and social care services assessments of the level of satisfaction experienced by adults with ID. Data gathered on 367 participants with ID in northern Italy supported a three-factor structure for the EQLI with reliability scores in the moderate to high range. Scores were psychometrically valid for participants who may be at risk of dissatisfaction with various QOL domains.
16	Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder. The predictive value of disability and support characteristics. *Autism*, *10*(5), 511-524. https://doi.org/10.1177/1362361306066604	A study of 58 individuals with HF-ASD used self-reported measures to reveal that supportive characteristics are related to QOL in adults with ASD. Disability characteristics are not otherwise confirming poor outcomes in adults with high functioning ASD using a unidimensional outcome domain.
17	Riley, A. W., Spiel, G., Coghill, D., Döpfner, M., Falissard, B., Lorenzo, M. J., Ralston, S. J. (2006). Factors related to Health-Related Quality of Life (HRQoL) among children with ADHD in Europe at entry into treatment. *European Child and Adolescent Psychiatry, 15*(1), 38-45. https://doi.org/10.1007/s00787-006-1006-9	HRQoL is rated using the Parent Report Form of the Child Health & Illness Profile-Child Edition (CHIP-CE) to assess the association between baseline factors & parent reported HRQoL of children with ADHD. Results showed a lower level of HRQoL for children with ADHD with clinical factors & family factors significantly impact HRQoL.
18	Singh, N. N., Lancioni, G. E., Winton, A. S., Fisher, B. C., Wahler, R. G., Mcaleavey, K., Sabaawi, M. (2006). Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism. *Journal of Emotional and Behavioral Disorders*, *14*(3), 169-177. http://doi.org/10.1177/10634266060140030401	This study evaluated the benefits of teaching parents of children with ASD parenting philosophies using a mindfulness approach. Data gathered from three parents for 12 weeks indicated a decrease in their child's aggression, noncompliance, self-injury. Results indicated an increase in mothers' satisfaction with their parenting skills & interactions with their children as shown by the *Subjective Units of Parenting Satisfaction* (SUPS) scale.
19	Stade, B., Stevens, B., Ungar, W., Beyene, J., & Koren, G. (2006). Health-related quality of life of Canadian children and youth prenatally exposed to alcohol. *Health and Quality of Life Outcomes, 4*(81). https://doi.org/10.1186/1477-7525-4-81	HRQoL of Canadian children & youth diagnosed with fetal alcohol spectrum disorders (N = 126) was analyzed using the Health Utilities Index Mark 3 (HUI3). The HRQoL score significantly lower for Canadian children & youth diagnosed with fetal alcohol spectrum disorders (*M* = 0.47) compared

		to the general Canadian population (M = 0.93); burden of prenatal exposure is profound.
20	Summers, J.A., Little, T., Turnbull, A., Poston, D., & Mannan, H. (2006). Perspectives of fathers and mothers of children in early intervention programmes in assessing family quality of life. *Journal of Intellectual Disability Research, 50*(12), 977-988. https://doi.org/10.1111/j.1365-2788.2006.00932.x	This study focused on 107 families of a child with a disability enrolled in an early intervention program. Data from the Beach Center FQOLS was analyzed using structural equation modeling. Results suggest that fathers & mothers respond similarly to the latent constructs; therefore, it holds promise for use with both parents in assessing FQOL across multiple family members.
21	Wang, Verdugo, M. A., Jordán de Urríes, F. B., Jenaro, C., Caballo, C., & Crespo, M. (2006). Quality of life of workers with an intellectual disability in supported employment. *Journal of Applied Research in Intellectual Disabilities*, *19*(4), 309-316. https://doi.org/10.1111/j.1468-3148.2006.00277.x	QOL of participants with ID working in supported employment (n =160) and in sheltered employed centers (n =72) evaluated using the QOL Scale & Typicalness Questionnaire. QOL was similar in both settings. Elevated levels of typicalness were associated with high QOL while more hours of direct support per week was linked to lower QOL.

	2007	**Summary of Work**
1	Aran, A., Shalev, R. S., Biran, G., & Gross-Tsur, V. (2007). Parenting style impacts on quality of life in children with cerebral palsy. *The Journal of Pediatrics, 151*(1). https://doi.org/10.1016/j.jpeds.2007.02.011	Parenting styles of 39 children with CP were examined using several systems resulting in a positive correlation between CHQ scores in physical summary, psychosocial summary, & family activities scale compared to the normative sample. Parenting factors are a significant factor in QOL for children with CP.
2	Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, *51*(9), 702-714. https://doi.org/10.1111/j.1365-2788.2007.00960.x	An examination of family resilience using a survey methodology of three open-ended questions from 175 parents/caregivers of a child with ASD resulted in finding specific resilience factors. Despite challenges, several families show evidence of resilience.
3	Burgess, A. F., & Gutstein, S. E. (2007). Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child and Adolescent Mental Health*, *12*(2), 80-86. https://doi.org/10.1111/j.1475-3588.2006.00432.x	A review of the literature with a brief description of the domains & indicators that contribute to QOL for people with ASD. There is a need for assessment of QOL outcomes for people with ASD beginning in childhood.
4	Chou, Y. C., Lin, L. C., Chang, A. L., & Schalock, R. L. (2007). The quality of life of family caregivers of adults with intellectual disabilities in Taiwan. *Journal of Applied Research in Intellectual Disabilities*, *20*(3), 200-210. https://doi.org/10.1111/j.1468-3148.2006.00318.x	An evaluation of QOL among 792 family carers of people with ID was conducted using the WHOQOL-BREF Taiwan version scale & ADL/IADL scales. The mean score for “physical” was highest & the “environment” was lowest. The strongest predictors of caregiving QOL was health status, family income, & the level of severity of disability.
5	Chou, Y. C., Schalock, R. L., Tzou, P. Y., Lin, L. C., Chang, A. L., Lee, W. P., & Chang, S. C. (2007). Quality of life of adults with intellectual disabilities who live with families in Taiwan. *Journal of Intellectual Disability Research*, *51*(11), 875-883. https://doi.org/10.1111/j.1365-2788.2007.00958.x	233 adults (16+) with mild ID from Taiwan participated in the study by completing Cross-Cultural QOL indicators (CCQOLI) scale with sociodemographic data including ADL/IADL scores. Each CCQOLI indicator had two sets of questions related to indicator's ‘*importance*’ & ‘*use*’, scored by respondent on a 4-point scale. The adults' individual characteristics, (IADL & educational level), were significant predictors for the ‘*importance*’ while the adults' perceptions of ‘*use*’ for overall QOL were significantly affected by his/her socio-economic data, that is, residence location & father's educational level.
6	Córdoba, L., Mora, A., Bedoya, Á., & Verdugo, M. A. (2007). Familias de adultos con discapacidad intelectual en Cali, Colombia: Desde el modelo de calidad de vida. / Families of adults with intellectual disability in Cali, Colombia: Using the model quality of life. *Psykhe: Revista De La Escuela De Psicología, 16*(2), 29-42. http://doi.org/10.4067/S0718-22282007000200003	Describes QOL of 158 families of adults with ID in Columbia using the Sociodemographic questionnaire & FQOL scale. FQOL was affected by the lack of opportunities for social inclusion in adults with ID.

7	Holburn, S., Cea, C. D., Coull, L., & Goode, D. (2007). Personal vs. proxy focus groups' perspectives on quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, *4*(3), 210-212. https://doi.org/10.1111/j.1741-1130.2007.00120.x	A focus group used to enhance the QOL of 119 individuals with ID living in small groups in Staton Island, NY. Self-advocates interested in enhancing QOL were distributed approximately evenly across home life, relationships, & community. Other groups were principally concerned about QOL as it pertained to home life.
8	Isaacs, B. J., Brown, I., Brown, R. I., Baum, N. T., Myerscough, T., Wang, M., et al. (2007). The international family quality of life project: Goals and description of a survey. *Journal of Policy and Practice in Intellectual Disability, 4*(3), 177-185. https://doi.org/10.1111/j.1741-1130.2007.00116.x	The International Family of Life Project extended the description of conceptualization of FQOL & developed a survey tool named FQOLS-2006. The survey focused on nine areas of family life with an exploration of the relation of six underlying concepts.
9	Landgraf, J. M. (2007). Monitoring quality of life in adults with ADHD. *Journal of Attention Disorders, 11*(3), 351-362. https://doi.org/10.1177/1087054707299400	ADHD Impact Module for Adults (AIM-A) questionnaire was developed & evaluated with six multiple item AIM scales on 317 participants using a multi-trait scaling analysis comparing AIM-A & the ADHD rating scale. Results indicated 100-80% scaling successes with psychometric findings being promising.
10	Lee, L., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2007). Children with autism: Quality of life and parental concerns. *Journal of Autism and Developmental Disorders*, *38*(6), 1147-1160. https://doi.org/10.1007/s10803-007-0491-0	This study analyzed cross-sectional parent reported data on QOL & parental concerns in 483 children with ASD compared to 6318 children with ADHD. Children with ASD are significantly less likely to attend church services, more likely to miss school, & less likely to participate in organized activities. Overall QOL scores were lower with families who have a child with ASD.
11	Livingston, M. H., Rosenbaum, P. L., Russell, D. J., & Palisano, R. J. (2007). Quality of life among adolescents with cerebral palsy: What does the literature tell us? *Developmental Medicine and Child Neurology, 49*(3), 225-231. https://doi.org/10.1111/j.1469-8749.2007.00225.x	A review of 20 original articles using a structured search of multiple databases focusing on QOL & HRQOL among adolescents with CP. Individuals with CP have a lower QOL & HRQOL compared to a normative population. There is limited research on factors associated with QOL & HRQOL of this age group.
12	Loureiro, A., Costa, F., & Costa, J. D. (2007). The impact of periodontal disease on the quality of life of individuals with Down syndrome. *Down Syndrome Research and Practice, 12*(1), 50-54. https://doi.org/10.3104/REPORTS.1998	Periodontal disease among 93 children & adolescents with Down syndrome studied using the Plaque Index & Oral Health Impact File. Negative effects on the QOL of participants with periodontal disease correlated with the clinical periodontal parameters making it necessary to address early periodontal monitoring.
13	Mactavish, J. B., MacKay, K. J., Iwasaki, Y., & Betteridge, D. (2007). Family caregivers of individuals with intellectual disability: Perspectives on life quality and the role of vacations. *Journal of Leisure Research*, *39*(1), 127. https://doi.org/10.1080/00222216.2007.11950101	A grounded theory approach using focus groups on 10 families highlighted the perspectives of family caregivers of individuals with ID. Personal health & basic need fulfillment was foundational elements, while unique health needs resulted in magnifying

		planning demands, limiting spontaneity & frequency associated with family vacations.
14	Martínez-Tur, V., Moliner, C., Sánchez, R., Ramos, J., Zurriaga, R., & Luque, O. (2007). Calidad de servicio y calidad de vida: Un estudio en servicios de atención a personas con discapacidad intelectual./ Service quality and quality of life: A study in services for people with mental disability. *Revista De Psicología Social Aplicada*, *17*(3), 273-285. https://www.researchgate.net/publication/235451996_Calidad_	This study's findings included a hierarchical regression analysis, which indicated that relational service quality has a more important effect than functional service quality in explaining the four dimensions of QOL (self-determination, defense of rights of people with mental disability, social inclusion & general QOL).
15	Matza, L. S., Johnston, J. A., Faries, D. E., Malley, K. G., & Brod, M. (2007). Responsiveness of the adult attention-deficit/hyperactivity disorder quality of life Scale (AAQoL). *Quality of Life Research, 16*(9), 1511-1520. https://doi.org/10.1007/s11136-007-9254-9	An examination of responsiveness of the ADHD QOL scale (AAQol) on 328 patients showing significant correlation between AAQoL & CGI-ADHD-S (r = 0.37 to 0.50), EWPS (r = 0.43 to 0.63), & CAARS (r= 0 .35, 0.62). Responsiveness was a change in symptoms of ADHD.
16	Mugno, D., Ruta, L., D'Arrigo, V. G., & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes*, *5*, 22. https://doi.org/10.1186/1477-7525-5-22	The WHOQOL-BREF questionnaire was used to assess 212 parents of children affected by PDD, CP, or ID compared to 77 controls. Parents of children with PDD have an impairment in physical activity, (p = .0001), social relationships (p = .0001), worse overall perceptions of their QOL (p = .0001) & health (p = .0005). Minor differences between ID, CP, & control groups.
17	Nota, L., Ferrari, L., & Soresi, S. (2007). Self-efficacy and quality of life of professionals caring for individuals with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *4*(2), 129-140. https://doi.org/10.1111/j.1741-1130.2007.00110.x	Questionnaires were completed by 146 professionals & 68 adults with ID to show that confidence in one's own ability to work in a team & establish productive & collaborative relationships with colleagues & superiors was a significant predictor of QOL. There were significant increments existing in emotional exhaustion & depersonalization.
18	Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research*, *51*(11), 850-865. https://doi.org/10.1111/j.1365-2788.2006.00939.x	A study incorporated 114 people with ID using the Evaluation of Self-Determination Instrument. Results indicated that the participants with more severe ID showed the lowest levels of self-determination, QOL, & social abilities with IQ scores significantly correlating with self-determining activities.
19	Plimley, L. A. (2007). A review of quality of life issues and people with autism spectrum disorders. *British Journal of Learning Disabilities*, *35*(4), 205-213. https://doi.org/10.1111/j.1468-3156.2007.00448.x	A review of the literature on QOL of those with ASD examined the core features of ASD & ways that QOL domains & assessments can be adapted to people with ASD. Further research is needed in creating a measurement tool refined to be sensitive to specific differences experienced by people with ASD.
20	Read, S. G., & Rendall, M. (2007). An open-label study of risperidone in the improvement of quality of life and treatment	Risperidone was studied to assess the QOL in the treatment of violent & self-injurious behaviors in 24

	of symptoms of violent and self-injurious behavior in adults with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 20*(3), 256-264. https://doi.org/10.1111/j.1468-3148.2006.00328.x	adults with moderate, severe, or profound ID for 12 weeks using the Aberrant Behaviour Checklist. An improvement in QOL measures (final visit: home life, p <.001; activity, p =.002; skills, p =.014) and significant improvement on ABC was seen.
21	Reiter, S., & Schalock, R. L. (2007). Applying the concept of quality of life to Israel's special education programs: A national curriculum for enhanced autonomy in students with special needs. *International Journal of Rehabilitation Research.* https://doi.org/10.1097/MRR.0B013E3282F45201	Development of a new national curriculum based on key QOL principles called 'cycle of internalized learning' explained including content, implementation, & assimilation to the Israeli culture. Objective was to enhance the autonomy & personal interpersonal relationships of students while incorporating academic studies in those with IDD.
22	Rosenbaum, P. L., Livingston, M. H., Palisano, R. J., Galuppi, B. E., & Russell, D. J. (2007). Quality of life and health-related quality of life of adolescents with cerebral palsy. *Developmental Medicine & Child Neurology, 49*(7), 516-521. https://doi.org/10.1111/j.1469-8749.2007.00516.x	The QOL and HRQoL of 203 adolescents with CP assessed using several instruments. QOL domain scores varied significantly by type of respondent & GMFCS level not a source of variation for QOL domain scores. It was significantly associated with HRQOL attributes, showing that QOL & HRQOL should be considered as separate dimensions of the lives of people with functional limitations.
23	Saito, Y., & Turnbull, A. (2007). Augmentative and alternative communication [AAC] practice in the pursuit of family quality of life: A review of the literature. *Research and Practice for Persons with Severe Disabilities*, *32*(1), 50-65. https://doi.org/10.2511/rpsd.32.1.50	A review of 13 studies on AAC practice analyzed family outcomes & perspectives to identify perceived importance in family interaction, parenting, physical well-being, disability-related support, & emotional well-being.
24	Schalock, R.L., Gardner, J. F., & Bradley, V. J. (2007). *Quality of life for people with intellectual and other developmental disabilities: Applications across individuals, organizations, systems, and communities.* Washington, DC: American Association on Intellectual and Developmental Disabilities.	The book discussed various issues in determining the importance of QOL, the measurement of personal outcomes, meeting psychometric measures, management strategies, & leadership to help develop services to enhance personal outcomes for those with ID.
25	Sherman, E. M., Slick, D. J., Connolly, M. B. and Eyrl, K. L. (2007). ADHD, neurological correlates and health-related quality of life in severe pediatric epilepsy. *Epilepsia*, *48*(6), 1083-1091. https://doi.org/10.1111/j.1528-1167.2007.01028.x	The aim of this study was to clarify presence of ADHD, its neurological correlates &the role of ADHD in & HRQOL of 203 children with severe epilepsy, using the ADHD Rating Scale –IV. Participants with ADHD-1 had more prevalence of localization related epilepsy. ADHD-C was associated more with generalized epilepsy with both groups having a two & four-fold likelihood of low HRQOF compared to non-ADHD children.
26	Strnadová, I. (2007). Stresové a resilientní činitele v kontextu kvality života rodin dětí s mentálním postižením./ Stressful and resilient factors in the context of quality of life in families with children with intellectual disability. *Psychológia a Patopsychológia Dieťaťa, 42*(3), 191-213.	An observation on coping strategies in a group of 63 adolescents with physical disabilities & 110 adolescents without handicap resulted in less acceptable coping strategies in individuals that are physically handicapped with an influence of gender

		on the type of coping strategy displayed for adolescent girls.
27	Turnbull, A.P. & Poston, D.J. & Minnes, Patricia. (2007). Providing supports and services that enhance a family's quality of life, *A Comprehensive Guide to Intellectual and Developmental Disabilities* (pp.561-571). https://www.researchgate.net/publication/285863944_Providing_supports_and_services_that_enhance_a_family's_quality_of_life	
28	Isaacs, B.J., Brown, I., Brown, R.I., Baum, N., Myerscough, T., Neikrug, S., Roth, D., Shearer, J. and Wang, M. (2007), The international family quality of life project: Goals and description of a survey tool. *Journal of Policy and Practice in Intellectual Disabilities, 4,* 177-185. https://doi.org/10.1111/j.1741-1130.2007.00116.x	This article discussed the FQoLS-2006, which focuses on 9 areas of family life: health, finances, family relationships, support from other people, support from disability-related services, influence of values, careers & planning for careers, leisure & recreation, & community interaction.
29	Turnbull, A. P., Summers, J. A., Lee, S.-H. and Kyzar, K. (2007). Conceptualization and measurement of family outcomes associated with families of individuals with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 346–356. https://doi.org/10.1002/mrdd.20174	A review comparing well-being, adaptation, & family functioning of 28 articles that indicated a lack of conceptual definitions, theory, & random representative samples associated with having a family member with ID. A focus is needed in new instrument development.
30	Yacubian-Fernandes, A., Ducati, L. G., Silva, M. V., Abramides, D. V. M., Perosa, G. B., Palhares, A., et al. (2007). Fatores envolvidos no desenvolvimento neuropsicologico e na qualidade de vida./ Crouzon syndrome: Factors related to the neuropsychological development and to the quality of life. *Arquivos De Neuro-Psiquiatria, 65*(2-B), 467-471. http://doi.org/10.1590/S0004-282X2007000300020	This study on 11 Infants with Crouzon syndrome focused on their mental development and its association with brain malformation, age, time of surgery, level of family environment, and parental education. Results indicate that the QOL is correlated with infants' neuropsychological development.

	2008	**Summary of Work**
1	Adler, L., Spencer, T., Levine, L., Ramsey, J., Tamura, R., Kelsey, D., Biederman, J. (2008). Functional outcomes in the treatment of adults with ADHD. *Journal of Attention Disorders, 11*(6), 720-727. https://doi.org/10.1177/1087054707308490	This study examined functional outcomes following a 6-month double-blind treatment of 410 adults with ADHD with either atomoxetine or placebo. Results found that following 6-month treatment with atomoxetine, adults with ADHD showed significantly greater improvement in functioning on disease-specific measures of QOL than patients treated with placebo.
2	Arnaud, C., White-Koning, M., Michelsen, S. I., Parkes, J., Parkinson, K., Thyen, U., Colver, A. (2008). Parent-reported quality of life of children with cerebral palsy in Europe. *Pediatrics, 121*(1), 54-64. https://doi.org/10.1542/peds.2007-0854	This cross-sectional survey research study of 818 children with CP aimed to find if the type & severity of the child's impairments & the family's psychosocial, social, & economic characteristics influenced parent-reported child QOL. Results found that parent reported QOL for children with CP was associated strongly with impairment, but not determined by impairment.
3	Brewin, B. J., Renwick, R., & Fudge Schormans, A. (2008). Parental perspectives of the quality of life in school environments for children with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities*, *23*(4), 242-252. https://doi.org/10.1177/1088357608322997	This study included 9 interviews with participants from a larger research project that examined the perspectives of parents regarding what factors contribute to or detract from their children's QOL at school. The following themes are awareness of AS in the school system, quality of social interaction, role of the teaching staff & professionals, & the role of the institution & educational structure.
4	Brown, I., Petrowski, N. T., Edwards, M., Isaacs, B. D., & Baum, N. (2008). *Family quality of life for social work practice: Lessons from the field of intellectual disabilities*. Unpublished paper, Faculty of Social Work, University of Toronto. https://www.academia.edu/23150235	This paper highlighted the QOL of 64 families of individuals with disabilities from a family-centered point of view using the FQOLS-2006 tool. Results determined the utility of a FQOL approach for future social work practices as it is a complex, muti-dimensional framework.
5	Buzatto, L. L., & Beresin, R. (2008). Quality of life of parents with Down syndrome children. *Einstein*, *6*(2), 175-81. https://www.researchgate.net/publication/26541905_Quality_of_life_of_parents_with_Down_syndrome_children	This cross-sectional study from 30 parents having children with Down syndrome examined their social & demographic features & QOL. Results found that the psychological domain had the lowest score, & the social domain had the highest score in the QOL evaluation.
6	Buys L., Boulton-Lewis G., Tedman-Jones J., Edwards H., Knox M., Bigby C. (2008). Issues of active ageing: Perceptions of older people with lifelong intellectual disability. *Australas. J. Ageing.* ***27***, 67–71. https://doi.org/10.1111/j.1741-6612.2008.00287.x	This study investigated the lived experiences of older people with IDD using semi-structured interviews of individuals with IDD (50 years & older). Interviews explored the meaning of active ageing for those with an IDD, which valued mental stimulation, companionship, reliable support & safety.
7	Corti, S., Leoni, M., Chiodelli, G., Fioriti, F., Croce, L., Buntinx, W. H. E., & Schalock, R. L. (2008). AAIDD and QOL models for intellectual and developmental disabilities: Outcomes in 11	

	residential services. *Journal of Intellectual Disability Research*, *52*, 791. [Conference/Meeting Abstract]	
8	Cuskelly, M., Hauser-Cram, P., & Van Riper, M. (2008). Families of children with Down syndrome: What we know and what we need to know. *Down Syndrome Research and Practice,* pp. 105-113. ISSN 0968-7912. https://www.researchgate.net/publication/43515279_Families_of_children_with_Down_syndrome_What_we_know_and_what_we_need_to_know	This article discusses about the issues faced by the families of children with Down syndrome, the need for a more balanced perspective acknowledging positive and negative aspects of Down syndrome, attention to the experiences of fathers, cross-cultural research, attention to aging families with longitudinal studies & need for statistical approaches that model change and test hypotheses about predictors of change in both parents & children.
9	Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *38*(4), 739-747. https://doi.org/10.1007/s10803-007-0441-x	This study utilized a multilinear regression & evaluated earlier studies focusing on adults with ASD who had poor to extremely poor outcomes. Young individuals with ASD had more opportunities to success & received better results because of this.
10	Ferrandi, A., Castellani, A., & Monchieri, S. (2008). Incidenza dell' approccio ri-abilitativo sulla qualità della vita nella disabilità intellettiva./ Rehabilitative approach influencing the quality of life in adults with intellectual disabilities. *Giornale Italiano Di Psicopatologia/ Italian Journal of Psychopathology*, *14*(4), 382-388. https://www.jpsychopathol.it/wp-content/uploads/2015/08/ferrandi1.pdf	This study evaluated both subjective & objective components of QOL of individuals with IDD suggested that the aim of therapeutic interventions should be to improve QOL. There is a need for more methodological rigorous studies to improve daily practice and content effectiveness.
11	Gerber, F., Baud, M. A., Giroud, M., & Carminati, G. G. (2008). Quality of life of adults with pervasive developmental disorders and intellectual disabilities*. Journal of Autism and Developmental Disorders, 38*(9), 1654-1665. https://doi.org/10.1007/s10803-008-0547-9	This study examined QOL & global evolution of individuals with pervasive developmental disorders in 3 separate groups by comparing individualized programs to traditional programs for IDD. Results found a good QOL was measured for all three groups.
12	Hartnett, E., Gallagher, P., Kiernan, G., Poulsen, C., Gilligan, E., & Reynolds, M. (2008). Day service programmes for people with a severe intellectual disability and quality of life: Parent and staff perspectives. *Journal of Intellectual Disabilities, 12*(2), 153-172. https://doi.org/10.1177/1744629508091340	This study examined the contributions of a community & campus-based day program to the QOL of program participants with a severe level of IDD from the perspective of parents and staff through qualitative interviews. Results revealed that community-based participants' new-found social roles, their hobbies and their work opportunities had a positive effect on their overall QOL.
13	Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *38*(4), 739-747. https://doi.org/10.1007/s10803-007-0441-x	This study utilized a multilinear regression & evaluated earlier studies focusing on adults with ASD who had poor to extremely poor outcomes. Young individuals with ASD had more opportunities to success & received better results because of this

14	Ferrandi, A., Castellani, A., & Monchieri, S. (2008). Incidenza dell' approccio ri-abilitativo sulla qualità della vita nella disabilità intellettiva./ Rehabilitative approach influencing the quality of life in adults with intellectual disabilities. *Giornale Italiano Di Psicopatologia/ Italian Journal of Psychopathology*, *14*(4), 382-388. https://www.jpsychopathol.it/wp-content/uploads/2015/08/ferrandi1.pdf	This study evaluated both subjective & objective components of QOL of individuals with IDD suggested that the aim of therapeutic interventions should be to improve QOL. There is a need for more methodological rigorous studies to daily practice & content effectiveness.
15	Gerber, F., Baud, M. A., Giroud, M., & Carminati, G. G. (2008). Quality of life of adults with pervasive developmental disorders and intellectual disabilities. *Journal of Autism and Developmental Disorders, 38*(9), 1654-1665. https://doi.org/10.1007/s10803-008-0547-9	This study examined QOL & global evolution of individuals with pervasive developmental disorders (PDD) in three separate groups by comparing individualized programs to traditional programs for IDD. Results found a good QOL was measured for all three groups.
16	Hartnett, E., Gallagher, P., Kiernan, G., Poulsen, C., Gilligan, E., & Reynolds, M. (2008). Day service programmes for people with a severe intellectual disability and quality of life: Parent and staff perspectives. *Journal of Intellectual Disabilities, 12*(2), 153-172. https://doi.org/10.1177/1744629508091340	This study examined the contributions of a community & campus-based day program to the QOL of program participants with a severe level of IDD from the perspective of parents & staff through qualitative interviews. Results revealed that community-based participants' new-found social roles, their hobbies and their work opportunities had a positive effect on their overall QOL.
17	Lee, L. C., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2008). Children with autism: Quality of life and parental concerns. *Journal of Autism and Developmental Disorders*, *38*(6), 1147-1160. https://doi.org/10.1007/s10803-007-0491-0	This study evaluated QOL & parental concerns in children with ASD during early childhood, childhood, & adolescence compared to children with ADD/ADHD & typical controls from a US national sample. Results found that families with children with ASD reported more profound QOL effects than families of children with ADD/ADHD.
20	Mick, E., Faraone, S. V., Spencer, T., Zhang, H. F., & Biederman, J. (2008). Assessing the validity of the quality of life enjoyment and satisfaction questionnaire—short form in adults with ADHD. *Journal of Attention Disorders, 11*(4), 504-509. https://doi.org/10.1177/1087054707308468	Assessment of the psychometric properties of the QOL Enjoyment & Satisfaction Questionnaire—Short Form (Q-LES-QSF) in adults with ADHD. Results supported the validity of the Q-LES-QSF as a measure of QOL in adults with ADHD.
21	Petrowski, N. T., Edwards, M., Isaacs, B. J., Baum, N., & Brown, I. (2008). Family quality of life: Preliminary analyses from an on-going project. *Journal on Developmental Disabilities, 14*(2), 111-114. https://www.proquest.com/docview/210915158?pq-origsite=summon	A description of data gathered as part of an ongoing project on QOL of families with one or more members with IDD. 64 caregivers from the Toronto Area interviewed using the FQOL Survey to identify strengths & challenges in life areas, including support from non- immediate family.
22	Ravindranadan, V., & Raju, S. (2008). Emotional intelligence and quality of life of parents of children with special needs. *Journal of the Indian Academy of Applied Psychology, 34*, 34-39. https://www.yumpu.com/en/document/view/5554794/emotional-intelligence-and-quality-of-life-of-parents-of-medind	This study targeted emotional intelligence & QOL of parents of children with special needs. 200 parents were examined through the Emotional Intelligence Scale & QOL Scale. Results indicated parents of children with disabilities have variance compared to the parents with children without disabilities.

23	Reiter, S., & Schalock, R. L. (2008). Applying the concept of quality of life to Israeli special education programs: A national curriculum for enhanced autonomy in students with special needs. *International Journal of Rehabilitation Research*, *31*(1), 13-21. https://doi.org/10.1097/mrr.0b013e3282f45201	This study described the design & development of guidelines & programs for a national core curriculum for special education in Israel as well as the success of the implementation of the program.
24	Mick, E., Faraone, S. V., Spencer, T., Zhang, H. F., & Biederman, J. (2008). Assessing the validity of the quality of life enjoyment and satisfaction questionnaire—short form in adults with ADHD. *Journal of Attention Disorders, 11*(4), 504-509. https://doi.org/10.1177/1087054707308468	Assessment of the psychometric properties of the QOL Enjoyment & Satisfaction Questionnaire—Short Form (Q-LES-QSF) in adults with ADHD. Results supported the validity of the Q-LES-QSF as a measure of QOL in adults with ADHD.
25	Petrowski, N. T., Edwards, M., Isaacs, B. J., Baum, N., & Brown, I. (2008). Family quality of life: Preliminary analyses from an ongoing project. *Journal on Developmental Disabilities, 14*(2), 111-114. https://www.proquest.com/docview/210915158?pq-origsite=summon	A description of data gathered as a part of an ongoing project that explored QOL of families with one or more member with IDD. 64 caregivers from the Toronto interviewed using the FQOL Survey to indicate strengths in certain life areas & challenges in other areas, including support from non-immediate family.
26	Ravindranadan, V., & Raju, S. (2008). Emotional intelligence and quality of life of parents of children with special needs. *Journal of the Indian Academy of Applied Psychology, 34*, 34-39. https://www.yumpu.com/en/document/view/5554794/emotional-intelligence-and-quality-of-life-of-parents-of-medind	This study examined emotional intelligence & QOL of 200 parents of children with special needs using the Emotional Intelligence Scale & QOL Scale. Results indicated parents of children with disabilities have variance compared to parents of typically developing children.
27	Reiter, S., & Schalock, R. L. (2008). Applying the concept of quality of life to Israeli special education programs: A national curriculum for enhanced autonomy in students with special needs. *International Journal of Rehabilitation Research*, *31*(1), 13-21. https://doi.org/10.1097/mrr.0b013e3282f45201	This study described the design & development of guidelines & programs for a national core curriculum for special education in Israel as well as the success of the implementation of the program.
28	Saviani-Zeoti, F., & Petean, E. B. L. (2008). A qualidade de vida de pessoas com deficiência mental leve./ Quality of life of people with mild intellectual disability. *Psicologia: Teoria e Pesquisa, 24*(3), 305-311. https://doi.org/10.1590/S0102-37722008000300006	This study aimed to understand 15 adults with mild IDD related to their QOL & their caregiver's opinions by using the WHOQOL-Bref. Results found that there weren't significant statistical differences between evaluations. People with IDs can talk about their own lives with optimism and realism.
29	Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning*, *31*(2), 181–190. https://doi.org/10.1016/j.evalprogplan.2008.02.001	This article describes the development of a QOL conceptual & measurement framework and summarizes how this framework is currently being used. Uses include both nationally & internationally to assess & report personal QOL-related outcomes, to guide quality improvement strategies, & to evaluate the effectiveness of those strategies.
30	Schalock, R. L., Verdugo, M. A., Bonham, G. S., Fantova, F., & Van Loon, J. (2008). Enhancing personal outcomes: Organizational strategies, guidelines, and examples. *Journal of Policy and Practice in Intellectual Disabilities*, *5*(4), 276-28 http://dx.doi.org/10.1111/j.1741-1130.2007.00135.x	This article summarized key aspects of mental models, assessment, service delivery practices, & quality improvement (QI) within a two-component framework: the concept of QOL & systems thinking.

31	Shelly, A., Davis, E., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., Graham, H. K. (2008). The relationship between quality of life and functioning for children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*(3), 199-203. https://doi.org/10.1111/j.1469-8749.2008.02031.x	This study examined the association between functioning & QOL domains for children with CP by surveying 205 parents of children with CP & 53 children with CP using the CP QOL Questionnaire for Children. Results showed that children with CP have the potential to report a high psychosocial QOL score despite poor functioning.
32	Smith, L. E., Greenberg, J. S., Seltzer, M. M., & Hong, J. (2008). Symptoms and behavior problems of adolescents and adults with autism: Effects of mother–child relationship quality, warmth, and praise. *American Journal on Mental Retardation*, *113*(5), 387-402. https://doi.org/10.1352%2F2008.113%3A387-402	Cross-lagged panel design used to investigate impact of positive family processes on change in ASD symptoms & behaviors among 149 co-residing mothers & their adolescent or adult child with ASD. Results found that a prominent level of relationship quality was associated with subsequent reductions in internalizing & externalizing problems as well as reductions in impairments in social reciprocity & repetitive behaviors.
33	White-Koning, M., Grandjean, H., Colver, A., & Arnaud, C. (2008). Parent and professional reports of the quality of life of children with cerebral palsy and associated intellectual impairment. *Developmental Medicine & Child Neurology, 50*(8), 618-624. https://doi.org/10.1111/j.1469-8749.2008.03026.x	This study examined parent-professional agreement in proxy-reports of child QOL & the factors associated with low child QOL in children with CP & associated IDD. Results determined elevated levels of stress in parenting negatively influenced parent reports of child QOL compared with professional reports. Child pain was associated with professionals rating lower than parents.
34	Zimmerman, F., & Endermann, M. (2008). Self-proxy agreement and correlates health-related quality of life in young adults with epilepsy and mild intellectual disabilities. *Epilepsy & Behavior, 13*(1), 202-211. https://psycnet.apa.org/doi/10.1016/j.yebeh.2008.02.005	This study investigated HRQOL in young adults with epilepsy & IDD by interviewing 36 individuals using the QOL in Epilepsy inventory (QOLIE-31), the Hospital Anxiety & Depression Scale, & the Neuroticism & Extraversion scales of the NEO Five-Factor Inventory. Results indicated that psychological treatment of negative affectivity & after critical life events in adolescence may improve HRQOL in young adults with epilepsy & mild IDD.

	2009	**Summary of Work**
1	Beadle-Brown, J., Murphy, G., & DiTerlizzi, M. (2009). Quality of life for the Camberwell cohort. *Journal of Applied Research in Intellectual Disabilities, 22*(4), 380-390. https://doi.org/10.1111/j.1468-3148.2008.00473.x	This study examined the QOL of the Camberwell Cohort, a total population sample of people with severe IDD &/or ASD through The Lifestyle Satisfaction Scale. It was combined with selected questions from the QOL Questionnaire & conducted with 12 people with IDD & 72 proxy respondents. Some support the widely held belief that QOL was lower for those with IDD & for those with challenging behavior.
2	Brown, I., & Brown, R. I. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1), 11-18. https://doi.org/10.1111/j.1741-1130.2008.00198.x	This article described what is known about choice, a concept included in QOL approach & set out a conceptualization of its two main components: available opportunities & choice-making. There was discussion of many practical issues & suggestions for application.
3	Brown, R. I. (2009). Guest editorial on quality of life and its application. *Journal of Policy and Practice in Intellectual Disabilities*, *6*, 1. https://doi.org/10.1111/j.1741-1130.2009.00204.x	This issue attempted to begin addressing concepts & ideas needed to be applied & evaluated through a series of articles that look at applications & ways of applying QOL & FQOL to real-life situations.
4	Brown, R.I., Schalock, R.& Brown I. (2009) Quality of life and its application to persons with intellectual disabilities and their families- introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1) 2-5. https://doi.org/10.1111/j.1741-1130.2008.00202.x	This article provides an overview of QOL conceptualization in the field of IDD, background information, & organizing framework for presenting concepts & concrete ideas for applying QOL. Results determined there is a need to identify relevant QOL evidence from the literature in a proactive way.
5	Burton-Smith, R., McVilly, K. R., Yazbeck, M., Parmenter, T. R., & Tsutsui, T. (2009). Quality of life of Australian family carers: Implications for research, policy, and practice. *Journal of Policy and Practice in Intellectual Disabilities, 6*(3), 189-198. https://doi.org/10.1111/j.1741-1130.2009.00227.x	This study investigated the burden of care, health, & subjective well-being experienced by 448 family carers supporting a relative with disability at home by completing a self-report demographic survey, the Family Caregiver Burden Inventory, the General Health Questionnaire, & the Personal Wellbeing Index. Results indicated the group of family carers were at substantial risk of social & economic disadvantage & mental health challenges.
6	Chou, Y. Schalock, R. (2009). Survey outcomes and cross-national comparisons of quality of life with respect to people with intellectual disabilities in Taiwan. *Journal of Policy and Practice in Intellectual Disabilities*, *6*, 7-10. https://doi.org/10.1111/j.1741-1130.2008.00200.x	This article administered the Cross-Cultural QOL Indicators Survey & the QOL Questionnaire in 2004 & 2005 to 481 adults with IDD who either were living with their family or residing within a facility. Results showed that the domain of "social inclusion" was the lowest for both adults using residential services & living with family.
7	Chou, Y. C., Pu, C. Y., Lee, Y. C., Lin, L. C., & Kröger, T. (2009). Effect of perceived stigmatization on the quality of life among ageing female family carers: A comparison of carers of adults	This study explored whether there are differences in the significant predictors of female ageing family carers' QOL between family carers of adults with ID

	with intellectual disability and careers of adults with mental illness. *Journal of Intellectual Disability Research*, *53*(7), 654-664. https://doi.org/10.1111/j.1365-2788.2009.01173.x	& family carers of adults with MI. Study was assessed by administering a structural survey interview to these family carers.
8	Davis, K. & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability, 34*(2), 153-162. https://doi.org/10.1080/13668250902874608	This study examined the contribution of child, family, & support characteristics to the QOL in 64 families of young children with disabilities. Results found that parental perceptions and experiences of family-centered professional support were one of the strongest predictors of FQOL.
9	De Wein, M., & Miller, L. K. (2009). The teaching-family model: A program description and its effects on the aggressive behaviors and quality of life of two adults with intellectual disabilities. *Journal of Positive Behavior Interventions*, *11*(4), 235–251. https://doi.org/10.1177/1098300709332344	This article described a program that may be effective for reducing the aggressive behaviors of two adults with IDs. Results suggested that an intervention anchored in teaching-family model (TFM) procedures was effective to reduce the mean value of physical aggression toward people or property & verbal aggression while improving QOL for both participants.
10	Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, *13*(4), 375-387. https://doi.org/10.1177/1362361309105658	This study investigated how child characteristics influence maternal parenting stress & psychological distress by evaluating mothers & developmental-age matched preschool-aged children with ASD & DD. Results found that children's problem behavior was associated with increased parenting stress & psychological distress in mothers in the ASD & DD groups.
11	Hematian, K., Alborzi, S., & Khayyer, M. (2009). Quality of life of Iranian vocational students with and without intellectual disability. *Psychological Reports, 105*(3), 738-746. https://doi.org/10.2466/pr0.105.3.738-746	This study compared the attitudes of Iranian vocational students with & without IDD towards their QOL. Results found that the groups with IDD reported higher scores on the dimensions of life satisfaction, competency/productivity, & social belongingness/community integration.
12	Hornby, G. (2009). Review of quality of life for people with intellectual and other developmental disabilities: Applications across individuals, communities and systems. *International Journal of Disability, Development and Education*, *56*(2), 196-197.	This article found what QOL issues were important in a person's life & developed services & supports that enhance personal outcomes of these individuals by presenting a data-driven model of QOL. Model is based on the best practices & brings a solid discussion on what QOL means today in the field of ID.
13	Isaacs, B. Clark, C. Correia, S. Flannery, J. (2009). Utility of logic models to plan quality of life outcome evaluations. *Journal of Policy and Practice in Intellectual Disabilities*, *6*, 52-61. https://doi.org/10.1111/j.1741-1130.2008.00197.x	This study evaluated how logic models can be used to link service components with relevant QOL outcomes at short-term, intermediate, & long-term points in service delivery. Integration of program logic models into an expanded organizational model defined how QOL data can influence decision-making about programs at the service, organizational, & system levels.

14	King, G., Baxter, D., Rosenbaum, P., Zwaigenbaum, L., & Bates, A. (2009). Belief systems of families of children with autism spectrum disorders or Down syndrome. *Focus on Autism and Other Developmental Disabilities*, *24*(1), 50-64. https://doi.org/10.1177/1088357608329173	This qualitative study involved 16 parents of children with ASD or DS who recently entered elementary school or who were in their early years of high school. Results found that these families adopted perspectives of optimism, acceptance, & appreciation, & striving to change the environment or to meet their children's needs.
15	Kober, R. Eggleton, I.R.C. (2009). Using quality of life to evaluate outcomes and measure effectiveness. *Journal of Policy in Intellectual Disabilities, 6*, 40-51. https://doi.org/10.1111/j.1741-1130.2008.00194.x	This article supports the emerging view that QOL is an outcome measure that can be used to assess service providers' performance through the implementation of a comprehensive performance measurement system. QOL is one of the outcome measures.
16	Lee, G. K., Lopata, C., Volker, M. A., Thomeer, M. L., Nida, R. E., Toomey, J. A., Smerbeck, A. M. (2009). Health-related quality of life of parents of children with high-functioning autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *24*(4), 227-239. https://psycnet.apa.org/doi/10.1177/1088357609347371	The physical & mental HRQOL of 89 parents of children with HFASDs was compared to 46 parents of children without disabilities through the completion of surveys set to measure demographics, parenting stress, coping, resources, & QOL. Results found that for parents of children with HFASDs, demographics & psychosocial variables accounted for a significant amount of variance.
17	LeRoy, B., Samuel, P. S., Bahr, P., Evans, P., & Deluca, M. (2009). PISA 2006 and the Participation of students with special needs from Baltic and South Eastern European countries. In OECD (Ed.) *Students with disabilities, learning difficulties and disadvantages in the Baltic States, South Eastern Europe and Malta: Educational policies and indicators* (pp. 127-158). Paris: OECD/European Communities. http://www.oecd-ilibrary.org/docserver/download/9109111ec007.pdf?expires=1491592919&id=id&accname=ocid177356&checksum=C69DE684837480A39E4EEF40807626D3	This chapter compares the outcomes of students with special educational needs in the Baltic and Southeastern European regions based on standardized data (PISA).
18	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*, 1448-1458. https://doi.org/10.1016/j.ridd.2009.07.005	This study examined the WHOQOL-BREF of caregivers caring for their children & adolescents with IDD through structural interviews of 597 caregivers of children/adolescents with IDD. Results indicated that caregivers of children & adolescents with IDD display a lower score than the general population due to a combination of stress, health & household income factors.
19	Mackelprang, Romel W. & Salsgiver, Richard O. (2009). *Disability: A diversity model approach in human service practice (2 ed.).* Chicago, Illinois: Lyceum Books, Inc. https://www.worldcat.org/title/disability-a-diversity-model-approach-in-human-service-practice/oclc/607121274	This book used an empowerment approach to working with individuals with disabilities to help fill a void in the available literature on this topic. Also, the book prepared those who work with individuals with disabilities to do so successfully while providing these individuals with a greater sense of independence & resilience.

20	Neece, C.L., Kraemer, B.R. & Blacher J. (2009). Transition satisfaction and family well-being among parents of young adults with severe intellectual disability. *Intellectual and Developmental Disabilities*, *47*(1), 31-43. https://doi.org/10.1352/2009.47:31-43	This study examined parent perspectives of transition for 128 young adults with severe ID. Results suggested that transition satisfaction is related to young adults, family, & environmental characteristics (strongest predictors of transition satisfaction).
21	Olson, H., Oti, R., Gelo, J., & Beck, S. (2009). "Family matters:" Fetal alcohol spectrum disorder and the family. *Developmental Disabilities Research Reviews, 15*, 235-249. https://doi.org/10.1002/ddrr.65	This article integrated multiple information sources to better understand the role of family factors in the outcome of individuals with FASD. Family is affected by raising a child with this lifelong condition, resulting in directions for an intervention with a family systems approach.
22	Petry, K., & Maes, B. (2009). Quality of life: People with profound intellectual and multiple disabilities. In J. Pawlyn & S. Carnaby (Eds.), *Profound intellectual and multiple disabilities: Nursing complex needs.* (pp. 15–36). Wiley-Blackwell. https://psycnet.apa.org/record/2009-01235-002	This chapter explored the current measurement of QOL of individuals with PIMD by using five major question forms of QOL measurement as a framework to summarize their status. The chapter then described how QOL concepts & measures were used as both process & content for helping individuals with PIMD to improve their lives.
23	Robertson, S. M. (2009). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly*, *30*(1). http://dx.doi.org/10.18061/dsq.v30i1.1069	This article examined challenges to QOL experienced by adults with ASD & explained how a neurodiversity perspective offers an important alternative to the deficit model of ASD. Results suggested the creation of a collaborative approach between professionals/researchers & adults with ASD to better develop meaningful solutions.
24	Saldaña, D., Álvarez, R. M., Lobatón, S., Lopez, A. M., Moreno, M., & Rojano, M. (2009). Objective and subjective quality of life in adults with autism spectrum disorders in southern Spain. *Autism*, *13*(3), 303-316. https://doi.org/10.1177/1362361309103792	Subjective & objective measures of QOL for adults with ASD was evaluated using questionnaires completed by 74 family members. Results indicated the need for additional support to families of adults with ASD & increased community-based resources.
25	Schippers, A. & van Boheemen, M. (2009). Family quality of life empowered by family-oriented support. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1), 19-24. https://doi.org/10.1111/j.1741-1130.2008.00195.x	The article described positive practices in supporting young adults with IDD by recognizing their plans based on partnerships, the concept of QOL, & community support among 9 different families over a 2-year period. Results found importance in partnerships among the participants. All parties involved needed extra support to enhance overall QOL.
26	Shu, B. C. (2009). Quality of life of family caregivers of children with autism: The mother's perspective. *Autism*, *13*(1), 81-91. https://doi.org/10.1177/1362361307098517	This study explored the relationship between the QOL & feeling of 104 mothers of a child with ASD that completed questionnaires, including the WHOQOL-BREF. Results found that mother's feeling, history of chronic disease & religion were

		related to QOL in these mothers of children with ASD.
27	Verdugo, M.A. Schalock, R.L. (2009). Quality of life: From concept to future applications in the field of intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *6*, 62-64. http://dx.doi.org/10.1111/j.1741-1130.2008.00201.x	This study presented the QOL conceptual & measurement framework to assess & report personal outcomes, to guide quality improvement strategies, to evaluate the effectiveness of those practices & strategies, & to report about a QOL questionnaire composed of 861 participants with IDD. Study utilized factorial analysis to show that the QOL Integral scale is reliable & valid.
28	Wang, M., & Brown, R.I. (2009). Family quality of life: A framework for policy and social service provisions to support families of children with disabilities. *Journal of Family Social Work*. *12*(2), 144-167. https://doi.org/10.1080/10522150902874842	This article provided an overview of FQOL conceptualization by introducing two conceptual frameworks that are influential in the international research literature of FQOL & individuals with IDD. Issues of FQOL applications to professions (special education & social work) include implications for policy, research, & practice with respect to family support for families of children with IDD.
29	Werner, S., Edwards, J.M., Baum, N., Brown, I., Brown, R.I., & Isaacs, B.J. (2009). Family quality of life among families with a member who has an intellectual disability: An exploratory examination of key domains and dimensions of the revised FQOL Survey. *Journal of Intellectual Disability Research*. *53*(6), 501-511. https://doi.org/10.1111/j.1365-2788.2009.01164.x	This study provided a descriptive analysis of the domains & dimensions of the FQOL of 35 families of an individual with an IDD in a large urban center using the FQOLS-2006. Descriptive analyses indicated need for further examination.
30	Werner, S. Edwards, M. Baum, N.T. (2009). Family quality of life before and after out-of-home placement of a family member with an intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, *6*(1), 32-39. https://doi.org/10.1111/j.1741-1130.2008.00196.x	This study examined FQOL of 16 caregivers of an individual with IDD and other diagnoses through an in-depth interview. Coping mechanisms included problem-focused & emotion-focused coping, as well as external support resources before & after residential placement. Results suggested that an out-of-home residential placement of a family member with an IDD both positively & negatively impacts the entire family.
30	Zuna, N. I., Turnbull, A., & Summers, J. A. (2009). Family quality of life: Moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities, 6*(1), 25-31. https://doi.org/10.1111/j.1741-1130.2008.00199.x	This article proposed a theory of FQOL designed to explain how various concepts influence variations in FQOL. Professionals might apply theoretical propositions to their practice. FQOL theoretical model can serve to enable practitioners to examine which family, ecological, & programmatic variables are changeable to positively impact FQOL.

	2010	**Summary of Work**
1	Allik, H., Larsson, J., & Smedje, H. (2010). Health-related quality of life in parents of children with Asperger syndrome and high-functioning autism. *Handbook of Disease Burdens and Quality of Life Measures*, 3625-3642. https://doi.org/10.1186%2F1477-7525-4-1	This study evaluated HRQOL in parents of school-aged children with AS & HFASD by utilizing the 12 Item Short Form Health Survey (SF-12) & determined that mothers, not fathers, reported impaired HRQOL. There was a relationship between maternal well-being & child behavior characteristics.
2	Beyer, S., Brown, T., Akandi, R., & Rapley, M. (2010). A comparison of quality of life outcomes for people with intellectual disabilities in supported employment, day services and employment enterprises. *Journal of Applied Research in Intellectual Disabilities, 23*(3), 290-295. https://doi.org/10.1111/j.1468-3148.2009.00534.x	This research compared subjective & objective QOL by using the Comprehensive QOL Scale & the Work Environment Scale. Comparison of work environment for adults with ID & without ID in supported employment, employment enterprises, & day services showed supported employment provided constructive occupation & better QOL for individuals with ID.
3	Billstedt, E., Gillberg, I. C., & Gillberg, C. (2010). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism: The International Journal of Research and Practice, 15*(1), 7–20. https://doi.org/10.1177/1362361309346066	This study measured & studied social aspects & QOL of 120 individuals diagnosed with ASD in childhood, using a long-term prospective follow-up study of these individuals into late adolescence/early adulthood. Results found that the majority remained dependent on their caregivers for support in education, accommodation, & occupational situations. QOL was reported positive.
4	Brown, R. I., Hong, K., Shearer, J., Wang, M., & Wang, S. (2010). Family quality of life in several countries: Results and discussion of satisfaction in families where there is a child with a disability. In R. Kober (Ed.), *Enhancing the Quality of Life of People with Intellectual Disability: From Theory to Practice*. New York: Springer. http://dx.doi.org/10.1007/978-90-481-9650-0_20	Study examined QOL by describing wide range of variables such as family, age, form of disability, place of origin, & types of support that are needed for children with IDD. Results found that both internal aspects of family life are highly relevant in terms of QOL of children with IDD.
5	Buntinx, W. H. E., & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities, 7*(4), 283-294. https://doi.org/10.1111/j.1741-1130.2010.00278.x	The models of human functioning, support, & QOL (American Association on IDD; International Classification of Functioning, Disability, & Health) was discussed in terms of their implications for professional clinical & service good practice.
6	Chou, Y., Pu, C., Kröger, T., & Fu, L. (2010). Caring, employment, and quality of life: Comparison of employed and non-employed mothers of adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 115*(5), 406-420. https://doi.org/10.1352/1944-7558-115.5.406	This study determined the effects of caregiving on mothers with different employment statuses of adults with IDD by studying 302 working-age mothers with adult children with IDD. Results found unemployed mothers were more likely to have lower levels of QOL compared to mothers who were employed fulltime.
7	Claes, C., Van Hove, G., van Loon, J., Vandevelde, S., & Schalock, R. L. (2010). Quality of life measurement in the field of intellectual disabilities: Eight principles for assessing quality	This article established 8 principles related to personal outcomes in the field of IDD. QOL assessment instrument should be based on an

	of life-related personal outcomes. *Social Indicators Research, 98*(1), 61-72. http://dx.doi.org/10.1007/s11205-009-9517-7	empirically derived QOL conceptual & measurement framework/model.
8	Danckaerts, M., Sonuga-Barke, E. J., Banaschewski, T., Buitelaar, J., Döpfner, M., Hollis, C., Coghill, D. (2010). The quality of life of children with attention deficit/hyperactivity disorder: A systematic review. *European Child & Adolescent Psychiatry, 19*(2), 83-105. https://doi.org/10.1007/s00787-009-0046-3	This review of earlier literature focused on QOL in children & young adults with ADHD. Results found that ADHD connects to QOL especially when seen from a parents' perspective. QOL outcomes should be included in future treatment studies.
9	Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health and Development, 36*(1), 63-73. https://doi.org/10.1111/j.1365-2214.2009.00989.x	This study examined QOL of caregivers for children with CP, determined whether the impact of caring for a child with CP changes from childhood to adolescence, & discovered that caring for a child with CP affects a parent's physical well-being, social well-being, freedom & independence, family well-being & financial stability.
10	Fahey, Á., Walsh, P. N., Emerson, E., & Guerin, S. (2010). Characteristics, supports, and quality of life of Irish adults with intellectual disability in life-sharing residential communities. *Journal of Intellectual and Developmental Disability, 35*(2), 66-76. https://doi.org/10.3109/13668251003724635	This study compared quality & outcomes for 29 residents with an IDD across Camphill communities in Ireland. Results suggested that the value of applying distinctive benefits of life-sharing communities in more typical residential settings for people with ID should be investigated further to inform current policy debates.
11	García-Villamisar, D. A., & Dattilo, J. (2010). Effects of a leisure programme on quality of life and stress of individuals with ASD. *Journal of Intellectual Disability Research*, *54*(7), 611-619. https://doi.org/10.1111/j.1365-2788.2010.01289.x	This study examined leisure as a contributor of QOL in adults with ASD. A repeated measures design measured the effects of a one-year group leisure program intended to facilitate interaction with media, engagement in exercise, playing games & doing crafts, attending events, & participating in recreation activities for stress & QOL of 37 participants. Results found that participation in recreation activities positively influenced the stress & QOL of adults with ASD.
12	González-Agüero, A., Vicente-Rodríguez, G., Moreno, L. A., Guerra-Balic, M., Ara, I., & Casajus, J. A. (2010). Health-related physical fitness in children and adolescents with Down syndrome and response to training. *Scandinavian Journal of Medicine and Science in Sports*, *20*(5), 716-724. https://doi.org/10.1111/j.1600-0838.2010.01120.x	Review of previous on health-related physical fitness in children & adolescents with Down syndrome. Results indicate need for more research on children & adolescents with Down syndrome is necessary.
13	Kalay, L., Fujimori, S., Suzuki, H., Minamoto, K., Ueda, K., Wei, C.-N., Tomoda, A., Harada, K., Ueda, A. (2010). Description of environmental determinants of quality of life in children with intellectual disability in Japan using the Delphi technique. *Environmental Health and Preventive Medicine*, *15*(2), 73–83. https://doi.org/10.1007%2Fs12199-009-0109-6	The present study defined the framework of an environment conducive to the well-being of children with IDD as 71participants completed a questionnaire of 31 items. Support from family members at home, school (classmates & teachers), & government policies as the most

		important components for the improvement of QOL for children with IDD.
14	Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2010). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *41*(9), 1214-1227. https://doi.org/10.1007/s10803-010-1140-6	This study compared HRQOL scores of caregivers of children with ASD to those of the general US population & identified factors that influence HRQOL. Results found that the use of multi-pronged intervention approach that incorporates components aimed at improving family functioning, increasing support services, & assisting caregivers in developing healthy coping skills will influence factors for HRQOL.
15	Kuhlthau, K., Orlich, F., Hall, T. A., Sikora, D., Kovacs, E. A., Delahaye, J., & Clemons, T. E. (2010). Health-related quality of life in children with autism spectrum disorders: Results from the autism treatment network. *Journal of Autism and Developmental Disorders*, *40*(6), 721-729. https://doi.org/10.1007/s10803-009-0921-2	The study examined previous study focusing on HRQOL of 286 children with ASD. Results found that these children reported significantly lower HRQOL compared to children with chronic conditions. HRQOL scores related to: internalizing & externalizing problems, repetitive behaviors, social responsiveness, & adaptive behaviors in children with ASD.
16	McDougall, J., Evans, J., & Baldwin, P. (2010). The importance of self-determination to perceive quality of life for youth and young adults with chronic conditions and disabilities. *Remedial and Special Education*, *31*(4), 252-260. https://doi.org/10.1177/0741932509355989	This study explored the relationship between self-determination & perceived QOL for 34 young adults with chronic conditions & disabilities through the Life Satisfaction Index—Adolescents & the Arc's Self-Determination Scale. Self-determination was associated with QOL overtime.
17	Schmidt, S., Power, M., Green, A., Lucas-Carrasco, R., Eser, E., Dragomirecka, E., Fleck, M. (2010). Self and proxy rating of quality of life in adults with intellectual disabilities: Results from the DISQOL study. *Research in Developmental Disabilities, 31*(5), 1015-1026. https://doi.org/10.1016/j.ridd.2010.04.013	This study evaluated self & proxy reports of QOL in people with IDD with the WHOQOL-BREF. Results indicated a significant moderate association between the persons' QOL assessment & the assessment of the QOL domains.
18	Tarsuslu, T., & Livanelioglu, A. (2010). Relationship between quality of life and functional status of young adults and adults with cerebral palsy. *Disability and Rehabilitation, 32*(20), 1658-1665. https://doi.org/10.3109/09638281003649904	The study investigated the relation between HRQOL & functional status in 45 individuals with CP by utilizing 5 different systems, as outcome measures. Results found that young adults with CP were more affected by parameters related to physical condition. For adults with CP, psychological & emotional aspects may be more important indicators related to HRQOL.
19	Totsika, V., Felce, D., Kerr, M., & Hastings, R. P. (2010). Behavior problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism. *Journal of Autism and Developmental Disorders*, *40*(10), 1171-1178. https://doi.org/10.1007/s10803-010-0975-1	This study evaluated outcomes associated with ASD in older adulthood as well as older adults with an IDD. Results discovered older adults with ASD did not differ from those with IDD in terms of behavior problems, psychiatric disorder, & QOL. Adults with ASD were associated with

		decreased adaptive skills, not the presence of ASD.
20	Van Der Slot, W. M., Nieuwenhuijsen, C., Van Den Berg-Emons, R. J., Wensink-Boonstra, A. E., Stam, H. J., & Roebroeck, M. E. (2010). Participation and health-related quality of life in adults with spastic bilateral cerebral palsy and the role of self-efficacy. *Journal of Rehabilitation Medicine, 42*(6), 528-535. https://doi.org/10.2340/16501977-0555	This cross-sectional study assessed participation & HRQOL in 56 adults with bilateral spastic CP & explored associations with self-efficacy by using a multivariate logistic regression analysis. A considerable number of adults with bilateral spastic CP encountered difficulties in social participation & perceived HRQOL for physical function.
21	Van Loon, J., Claes, C., Vandevelde, S., Van Hove, G., & Schalock, R. L. (2010). Assessing individual support needs to enhance personal outcomes. *Exceptionality*, *18*(4), 193-202. http://dx.doi.org/10.1080/09362835.2010.513924	This article discussed the relationship between individuals with IDD & the education & human service organization services supporting paradigm, the QOL concept, & the evaluation of personal outcomes. Data can be aligned with QOL–related core domains to establish individualized support systems that enhance personal outcomes.
22	Walsh, P. N., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R. L., & Moseley, C. (2010). Supported accommodation for people with intellectual disabilities and quality of life: An overview. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(2), 137-142. https://doi.org/10.1111/j.1741-1130.2010.00256.x	Review of research published between 1995 & 2005 to: (1) review outcomes of deinstitutionalization & post institutionalization studies; (2) examine instruments used to measure outcomes for individuals; & (3) compare costs/benefits of models of supported accommodation.
23	Wang, M., Schalock, R. L., Verdugo, M. A., & Jenaro, C. (2010). Examining the factor structure and hierarchical nature of the quality of life construct. *Journal Information, 115*(3). https://doi.org/10.1352/1944-7558-115.3.218	This study evaluated 769 individuals with mild/moderate IDD from 15 countries in 4 geographic regions that completed a multidimensional QOL questionnaire. Results demonstrated the presence of a single second-order factor in QOL through confirmatory factor analysis & the comparison of two alternative second order QOL factor models.
24	Weiss, M. D., Gibbins, C., Goodman, D. W., Hodgkins, P. S., Landgraf, J. M., & Faraone, S. V. (2010). Moderators and mediators of symptoms and quality of life outcomes in an open-label study of adults treated for attention-deficit/hyperactivity disorder. *The Journal of Clinical Psychiatry, 71*(04), 381-390. https://doi.org/10.4088/jcp.08m04709pur	This article assessed moderators & mediators of symptoms & QOL outcomes of the QOL, Effectiveness, Safety, & Tolerability (QU.E.S.T.) study designed to evaluate the effectiveness of long-acting amphetamines in adults with ADHD. Results revealed community practice settings & satisfaction with medication is a direct measure of the complex interplay of symptom change, tolerability, & patient perception of treatment.
25	Young, N. L., Rochon, T. G., Mccormick, A., Law, M., Wedge, J. H., & Fehlings, D. (2010). The health and quality of life outcomes among youth and young adults with cerebral palsy. *Archives of Physical Medicine and Rehabilitation, 91*(1), 143-148. https://doi.org/10.1016/j.apmr.2009.08.152	This cross-sectional survey described the health & QOL of youth & young adults who have CP to assess the severity, age, & sex on these outcomes. Results determined that the observed health & QOL scores were much lower than

		those previously reported in the literature. Youth & adults with CP have limited health status, & health care is needed for the rest of their lives.
26	Zuna, N. I., Summers, J. A., Turnbull, A. P., Hu, X., & Zu, S. (2010). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities: From theory to practice* (pp. 241-278). New York: Springer. http://dx.doi.org/10.1007%2F978-90-481-9650-0_15	This chapter focused on FQOL theory for families of children with IDD & described FQOL as an interactive process in which individual family member demographics, characteristics, & beliefs interact with family-unit dynamics. The theoretical FQOL model served as a guide for researchers to generate multiple testable theoretical statements.

	2011	**Summary of Work**
1	Gameren-Oosterom, H. B., Fekkes, M., Buitendijk, S. E., Mohangoo, A. D., Bruil, J., & Wouwe, J. P. (2011). Development, problem behavior, and quality of life in a population based sample of eight-year-old children with Down syndrome. *PLOS ONE, 6*(7). https://doi.org/10.1371/journal.pone.0021879	This study analyzed children with Down syndrome over a 3-year period, investigating levels of development, problem behavior, & HRQOL compared to typically developing children. Results indicate the children with Down syndrome have an average developmental delay of 4 years, more often have emotional & behavioral problems, & have a less favorable HRQOL compared with controls.
2	Gerber, F., Bessero, S., Robbiani, B., Courvoisier, D. S., Baud, M. A., Traoré, M. C., & Galli Carminati, G. (2011). Comparing residential programmes for adults with autism spectrum disorders and intellectual disability: Outcomes of challenging behavior and quality of life. *Journal of Intellectual Disability Research*, *55*(9), 918-932. https://doi.org/10.1111/j.1365-2788.2011.01455.x	This longitudinal study evaluated changes in adults with ASD & adults with ID who had been integrated into two residential programs: ASD Program with a Structured Method (PAMS) vs. traditional program for ID (No-PAMS) for 2-19 years. Results found that the PAMS program had a positive & indirect influence on QOL by reducing challenging behaviors in adults with ASD.
3	Glicksman, S. (2011). Supporting religion and spirituality to enhance quality of life of people with intellectual disability: A Jewish perspective. *Intellectual and Developmental Disabilities*, *49*(5), 397–402. https://doi.org/10.1352/1934-9556-49.5.397	This review of literature explored the effects of religion in the lives of individuals with IDs as communal affairs & coping strategies.
4	Hu, X., Summers, J. A., Turnbull, A. P., & Zuna, N. (2011). The quantitative measurement of family quality of life: A review of available instruments. *Journal of Intellectual Disability Research*, *55*, 1098–1114. https://doi.org/10.1111/j.1365-2788.2011.01463.x	This article explored the disparity of scale development approaches between families with children with disabilities & families with children without disabilities. The study aimed to improve the measurements of FQOL in the disability field. Results discovered future researchers should consider implications from family instruments used in the healthcare & general family fields.
5	Hu, X., Wang, M., & Fei, X. (2011). Family quality of life of Chinese families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, *56*(1), 30-44. https://doi.org/10.1111/j.1365-2788.2011.01391.x	This study suggested a cross-cultural factor structure comparability of FQOL between among 442 Chinese families l with children with ID living in rural and urban Bejing. Results from the FQOL Scale call for further examination of family-centered services as mediators in FQOL outcomes.
6	Isaacs, B., Wang, M., Samuel, P., Ajuwon, P., Baum, N., Edwards, M., & Rillotta, F. (2011). Testing the factor structure of the Family Quality of Life Survey - 2006. *Journal of Intellectual Disability Research, 56*(1), 17-29. https://doi.org/10.1111/j.1365-2788.2011.01392.x	This study used samples to test the domain structure of the FQOLS-2006 using confirmatory factor analysis. Each domain on the survey can be reliably measured by the following four dimensions: opportunities, initiative, attainment, & satisfaction.
7	Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning and health-related quality of life. *Families, Systems, & Health, 29*(3), 232. https://doi.org/10.1037/a0025341	This study explored parenting stress, family functioning, & physical & mental health of parents of children with ASD by completing a Web-based survey. Results found that there may be differences in mothers' & fathers' perceptions &

		expectations about family functioning. This difference needs to be explored & applied when working with families of children with ASD.
8	Kober, R., & Wang, M. (Eds). (2011). Special issue on family quality of life. *Journal of Intellectual Disability Research*, *55,* 1093–1184.	This article reviewed trends in family support & the development of FQOL measurements in a more specific manner by providing conceptual background & detailed context.
9	Moyson, T., & Roeyers, H. (2011). The quality of life of siblings of children with autism spectrum disorder. *Exceptional Children*, *78*(1), 41-55. https://doi.org/10.1177/001440291107800103	This study investigated how siblings of children with ASD describe & define their QOL by using a qualitative research design, which included in-depth interviews. Results discovered that siblings of children with ASD can define their QOL, that the characteristics of ASD give the siblings' experience a highly personal interpretation, & that the sibling QOL concept can be used to support siblings of children with ASD.
10	Oliveira, E. D. F., & Limongi, S. C. O. (2011). Quality of life of parents/caregivers of children and adolescents with Down syndrome. *Jornal da Sociedade Brasileira de Fonoaudiologia*, *23*(4), 321-327. https://doi.org/10.1590/s2179-64912011000400006	This study assessed the QOL of caregivers of children & adolescents with Down syndrome. Results indicated that the environment domain & the socio-demographic variables "education degree" & "socio-economic level" are the aspects that influence their QOL.
11	Rizk, S., Pizur-Barnekow, K., & Darragh, A. R. (2011). Leisure and social participation and health-related quality of life in caregivers of children with autism. *OTJR: Occupation, Participation and Health*, *31*(4), 164-171. https://doi.org/10.3928/15394492-20110415-01	This cross-sectional study compared HRQOL in 33 mothers of children with ASD to examine the relationship between engagement in leisure, social occupations, & HQOL in mothers of children with ASD. Results found there is an inverse relationship between participation in leisure & social occupations with HRQOL.
12	Samuel, P. S., Hobden, K. L., & Leroy, B. W. (2011). Families of children with autism and developmental disabilities: A description of their community interaction. *Research in Social Science and Disability and Community*, 49-83. https://doi.org/10.1108/S1479-3547(2011)0000006006	This article described patterns & dimensions of community interaction of typically underserved families of children with ASD & other DDs within a FQOL context by utilizing the FQoLS-2006. Data derived from the caregivers of the children with disabilities (92% of which were mothers). Results found families of children with ASD reported lower attainment of community interaction when compared to families of children with other DDs.
13	Schalock, R. L., Keith, K. D., Verdugo, M. Á., & Gómez, L. E. (2011). Quality of life model development and use in the field of intellectual disability. *Enhancing the Quality of Life of People with Intellectual Disabilities*, 17-32. http://dx.doi.org/10.1007/978-90-481-9650-0_2	This article took the QOL construct from a philosophical concept to a measurable construct, & from a measurable construct to an operational model supported by considerable data. Data served as a basis for application & hypothesis testing.
14	Shipman, D. L., Sheldrick, R. C., & Perrin, E. C. (2011). Quality of life in adolescents with autism spectrum disorders: Reliability	This study examined the reliability & validity of self-reported QOL among 39 adolescents with ASDs

	and validity of self-reports. *Journal of Developmental and Behavioral Pediatrics, 32*(2), 85-89. https://doi.org/10.1097/dbp.0b013e318203e558	using a validated QOL measure, Pediatric QOL Inventory. Results were compared with normative data, finding that adolescents with ASDs can report on their own QOL in a valid & reliable manner.
15	Steel, R., Poppe, L., Vandevelde, S., Van Hove, G., & Claes, C. (2011). Family quality of life in 25 Belgian families: Quantitative and qualitative exploration of social and professional support domains. *Journal of Intellectual Disability Research*, *55*, 1123–1135. https://doi.org/10.1111/j.1365-2788.2011.01433.x	This article reviewed a study on FQOL of 25 caregivers focusing on the development of support strategies for young & adolescent siblings of persons with IDs by utilizing the FQOLS-2006. Results discovered the importance of adequate professional support for each family's individual needs.
16	Svraka, E., Loga, S., & Brown, I. (2011). Family quality of life: Adult school children with intellectual disabilities in Bosnia and Herzegovina. *Journal of Intellectual Disability Research*, *55*(12), 1115-1122. https://doi.org/10.1111/j.1365-2788.2011.01434.x	This study provided initial data on QOL for families with adult children who have IDD by utilizing the FQOLS-2006 to main caregivers of 35 families with adult children with ID. Results provided initial data for FQOL, suggestions for improving FQOL that have one or more members with ID. Results assisted in rejecting stereotypes & promoting inclusion of children with ID as well as the rights of their families.
17	Verdugo, M. Á., Gómez, L. E., Arias, B., & Schalock, R. L. (2011). The integral quality of life scale: Development, validation, and use*. Enhancing the Quality of Life of People with Intellectual Disabilities,* 47-60. http://dx.doi.org/10.1007/978-90-481-9650-0_4	This study presented the QOL conceptual & measurement framework that is currently being used: to implement QOL-related program practices, to assess & report personal outcomes, to guide quality improvement strategies, to evaluate the effectiveness of those practices & strategies, & to report about a QOL questionnaire.
18	Wang, M., & Kober, R. (2011). Embracing an era of rising family quality of life research. *Journal of Intellectual Disability Research*, *55*(12), 1093–1097. https://doi.org/10.1111/j.1365-2788.2011.01509.x	This editorial focuses on 16 articles representing the most current FQOL research from scholars across different regions of the world. Articles found that future measurement development should consider creating a new sub-scale or adding a domain to FQOL scales reflecting family dynamics to measure interactions & transactions among different family members.
19	Wong, P. K. S., Wong, D. F. K., Schalock, R. L., & Chou, Y. (2011). Initial validation of the Chinese Quality of Life Questionnaire Intellectual Disabilities (CQOL-ID): A cultural perspective. *Journal of Intellectual Disability Research*, *55*(6), 572-580. https://doi.org/10.1111/j.1365-2788.2011.01412.x	This study validated the Chinese QOL Questionnaire-ID, adapted from the QOL Questionnaire developed by Schalock & Keith, by recruiting 359 participants with mild/moderate ID. Results found that the Chinese QOL Questionnaire-ID may be a valid, useful instrument for measuring the QOL of Chinese people with ID.

	2012	**Summary of Work**
1	Agarwal, R., Goldenberg, M., Perry, R., & Ishak, W. W. (2012). The quality of life of adults with attention deficit hyperactivity disorder: A systematic review. *Innovations in Clinical Neuroscience*, *9*(5-6), 10–21. https://pubmed.ncbi.nlm.nih.gov/22808445/	A systematic review of 36 studies were analyzed to address factors which may influence QOL of adults with ADHD. Results determined that pharmacological treatment & early diagnosis have a positive impact on outcomes, long term prognosis, & QOL in adults with ADHD.
2	Ajuwan, P. M., & Brown, I. (2012). Family quality of life in Nigeria. *Journal of Intellectual Disability Research, 56*(1), 61-70. https://doi.org/10.1111/j.1365-2788.2011.01487.x	Descriptive study using the FQoLS-2006 administered to 80 family caregivers in Nigeria. The two main outcome measures, Attainment and Satisfaction, showed that three domains (Family relationships, Influence of values and Health) were sources of quality for families, but that three domains (Support from services, Support from others and Leisure) detracted from FQOL.
3	Choi, H., Van Riper, M., & Thoyre, S. (2012). Decision making following a prenatal diagnosis of Down syndrome: An integrative review. *Journal of Midwifery and Women's Health*, *57*(2), 156-164. https://doi.org/10.1111/j.1542-2011.2011.00109.x	A review of 11 studies evaluated the multitude of factors which influence pregnant women in making their decision to undergo an induced abortion following a prenatal diagnosis of Down syndrome.
4	Claes, C., Van Hove, G., Vandevelde, S., van Loon, J., & Schalock, R. (2012). The influence of supports strategies, environmental factors, and client characteristics on quality of life-related personal outcomes. *Research in Developmental Disabilities*, *33*(1), 96-103. https://doi.org/10.1016/j.ridd.2011.08.024	This study consisted of 186 individuals with ID & determined the role that available supports strategies, environmental factors, & client characteristics play in QOL outcomes by using a hierarchical multiple regression research design.
5	Clark, M., Brown, R.I., & Karrapaya. R. (2012). An initial look at the quality of life of Malaysian families that include children with disabilities. *Journal of Intellectual Disability Research* *56*(1), 45-60. https://doi.org/10.1111/j.1365-2788.2011.01408.x	This exploratory study evaluated FQOL of 52 Malaysian families of children with IDs through interviews, using the FQOLS-2006. The importance rating can be viewed as a determining factor in terms of QOL, & it played a critical role in supporting attainment of, & satisfaction with, FQOL, assuming opportunities, initiative & stability are adequate.
6	Cramm, J. M., & Nieboer, A. P. (2012). Longitudinal study of parents' impact on quality of life of children and young adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *25*(1), 20–28. https://doi.org/10.1111/j.1468-3148.2011.00640.x	This longitudinal study interviewed 147 parents at baseline and 108 parents at the second time point to determine predictors of QOL of their children & young adults (0-24 years) with ID in Netherlands. The QoL of children with ID was assessed with a proxy version of the Intellectual Disability Quality of Life *(IDQOL-24)* questionnaire. Significant predictors of children's QOL included social well-being of parents, changes in parents' and childrens' social well-being. Emotional well-being of children with ID, changes in children's and parents' emotional well-being also predicted QoL of children with ID.

7	Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities*, *33*(6), 2177-2192. https://doi.org/10.1016/j.ridd.2012.06.014	This article analyzed the FQOL construct & reviewed multiple studies on FQOL of families of children with various DDs to generate information about FQOL necessary to inform future policy & clinical practice.
8	Gullone, E., & Cummins, R. (Eds.). (2012). *The universality of subjective wellbeing indicators: A multi-disciplinary and multi-national perspective.* http://dx.doi.org/10.1007/978-94-010-0271-4	This book explored universality, assessment, development & maintenance of subjective wellbeing by evaluating factors that influence QOL. Factors include the following: residential care, economic wealth, & work-related variables.
9	Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *The Canadian Journal of Psychiatry*, *57*(5), 275-283. https://doi.org/10.1177/070674371205700502	This article found that adults with ASD are at a slight disadvantage in employment, social relationships, physical & mental health, societal support, & QOL.
10	Hu, X., Wang, M., & Fei, X. (2012). Family quality of life of Chinese families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, *56*(1), 30-44. https://doi.org/10.1111/j.1365-2788.2011.01391.x	Survey of 442 Chinese families of children with ID from urban & suburban Beijing indicated that living conditions, family income, & severity of disability of the child are predictors of families' satisfaction ratings of FQOL.
11	Karhula, M. E., Heiskanen, T., & Salminen, A. L. (2021). Systematic review: Need for high-quality research on occupational therapy for children with intellectual disability. *Scandinavian Journal of Occupational Therapy*, *30*(3), 261–277. https://doi.org/10.1080/11038128.2021.1968947	A systematic review of research published from 2000-2020 was undertaken to examine the effectiveness of occupational therapy interventions in enhancing participation in everyday life for children with ID. A literature search conducted using electronic databases indicated that occupational therapy in daily environments may improve participation in everyday activities for children with ID. Study highlights need for further research with rigorous designs and outcome measurements.
12	Isaacs, B., Wang, M., Samuel, P. S., Ajuwon, P., Baum, N., Edwards, M., et al. (2012). Testing the factor structure of the Family Quality of Life Survey–2006. *Journal of Intellectual Disability Research, 56*, 17-29. https://doi.org/10.1111/j.1365-2788.2011.01392.x	This study used data from four countries to test the domain structure of the FQOLS-2006, using confirmatory factor analysis. Each domain on the survey can be reliably measured by the following four dimensions: opportunities, initiative, attainment, & satisfaction.
13	Kheir, N., Ghoneim, O., Sandridge, A. L., Al-Ismail, M., Hayder, S., & Al-Rawi, F. (2012). Quality of life of caregivers of children with autism in Qatar. *Autism*, *16*(3), 293-298. https://doi.org/10.1177/1362361311433648	This study focused on the QOL of caregivers of children with ASD in Qatar. Results found that caregivers of children with ASD rated their health as poor & likely to get worse compared to the caregivers of children without ASD.

14	Kober, R., & Wang, M. (Eds.). (2012). Special issue on family quality of life. *Journal of Intellectual Disability Research*, *56*, 1–128.	This article reviewed trends in family support & the development of FQOL measurements in a more specific manner by supplying conceptual background & detailed context.
15	Moyson, T. and Roeyers, H. (2012). The overall quality of my life as a sibling is all right, but of course, it could always be better. Quality of life of siblings of children with intellectual disability: The sibling's perspectives. *Journal of Intellectual Disability Research*, *56*(1), 87-101. https://doi.org/10.1111/j.1365-2788.2011.01393.x	A qualitative research study (in-depth phenomenology-based interviews) to understand QOL as defined by siblings of children with ID. Data gathered from 50 siblings (mean age = 9 years) indicated the nine QOL domains: Joint activities, mutual understanding, private time, acceptance, forbearance, trust in well-being, exchanging experiences, social support & dealing with the outside world.
16	Roberts, L., Bourke, J., & Leonard, H. (2012). Family functioning in families with a child with Down syndrome: A mixed methods approach. *Journal of Intellectual Disability Research*, *56*(10), 961-973. https://doi.org/10.1111/j.1365-2788.2012.01561.x	This mixed-methods study examined factors predicting family functioning by gathering data from 224 primary caregivers of children (4-25 years) with Down syndrome in Western Australia. The effect of maladaptive and autism-spectrum behaviors on family functioning was examined quantitatively, the impact of having a child with Down syndrome on family holidays, family activities and general family functioning was examined qualitatively.
17	Rillotta, F., Kirby, N., Shearer, J., & Nettelbeck, T. (2012). Family quality of life of Australian families with a member with an intellectual/developmental disability. *Journal of Intellectual Disability Research*, *56*(1), 71-86. https://doi.org/10.1111/j.1365-2788.2011.01462.x	Cross-sectional survey research of 42 caregivers interviewed using the FQOLS-2006 to better inform service provisions & enhance QOL of family caregivers of individuals with IDD in South Australia.
18	Romney, D.R., Brown, R.I., Fry, P.S. (2012). Improving the quality of life: Prescriptions for change. In Romney, D.R., Brown, R.I., Fry, P.S. (Eds). *Improving the quality of life: Recommendations for people with or without disabilities.* Kluwer Academic Publishers. https://books.google.com.ag/books?id=aZW8kQEACAAJ&source=gbs_navlinks_	This book focused on QOL for individuals with disabilities as it expands upon their challenges, evaluates different controversies, solves ongoing issues, & draws conclusions to assist individuals with disabilities in improving their QOL.
19	Salmon, J. V., & Buetow, S. A. (2012). An exploration of the experiences and perspectives of New Zealanders with fetal alcohol spectrum disorder. *J Popul Ther Clin Pharmacol*, *19*(1), e41-e50. https://pubmed.ncbi.nlm.nih.gov/22394603/	This study used a mixed methods design to assess 14 participants with FASD or fetal alcohol effects. Purpose was to explore & understand the daily challenges of New Zealand individuals with FASD.
20	Samuel P. S., Hobden K. L., LeRoy B. W., Lacey K. K. (2012). Analyzing family service needs to typically underserved families in the USA. *Journal of Intellectual Disability Research, 56,* 111-128. https://doi.org/10.1111/j.1365-2788.2011.01481.x	This cross-sectional study utilized the FQOL Survey (FQOLS-2006) to assess the need for resources & support services to empower families of children with disabilities (primarily low-income & minority families in the USA).
21	Samuel P. S., Rillotta F., Brown I. (2012). The development of family quality of life concepts and measures. *Journal of*	This article reviewed trends in family support & the development of FQOL measurements in a more

	Intellectual Disability Research, 56, 1-16. https://doi.org/10.1111/j.1365-2788.2011.01486.x	specific manner by providing conceptual background & detailed context.
22	Schalock, R. L., & Kiernan, W. E. (2012). *Habilitation planning for adults with disabilities.* https://www.barnesandnoble.com/w/habilitation-planning-for-adults-with-disabilities-robert-l-schalock/1000957583	This book further explored the QOL of adults with disabilities in the following domains: independence, productivity, community integration, historical treatment, current treatment, & trends.
23	Schäper, S., & Graumann, S. (2012). Aging and quality of life: Challenges and opportunities for people with intellectual disabilities. *Zeitschrift Für Gerontologie Und Geriatrie*, *45*(7), 630. https://doi.org/10.1007/s00391-012-0388-1	This article explored different ideas for the development of living conditions & the specific requirements or arrangements for elderly people with IDs in the coming years.
24	Sheldrick, R. C., Neger, E. N., Shipman, D., & Perrin, E. C. (2012). Quality of life of adolescents with autism spectrum disorders: Concordance among adolescents' self-reports, parents' reports, and parents' proxy reports. *Quality of Life Research*, *21*(1), 53-57. https://doi.org/10.1007/s11136-011-9916-5	This study consisted of 39 adolescents with ASDs & their parents who all completed the Pediatric QOL Inventory (PedsQL) to assess the difference of opinions between the parents of adolescents with ASDs & the adolescents with ASDs themselves regarding their overall QOL.
25	Şipoş, R., Predescu, E., Mureşan, G., & Iftene, F. (2012). The evaluation of family quality of life of children with autism spectrum disorder and attention deficit hyperactive disorder. *Applied Medical Informatics*, *30*(1), 1-8. https://www.researchgate.net/publication/244655001_	This article compared the QOL of families of children with disabilities by sampling (n = 65) children with ASD to (n = 49) children with ADHD using the FQOL Survey. Results determined that the parents of children with ADHD believe family relationships are less important for their overall FQOL; there were few opportunities to improve relations.
26	Strnadová, I., & Evans, D. (2012). Subjective quality of life of women with intellectual disabilities: The role of perceived control over their own life in self-determined behaviour. *Journal of Applied Research in Intellectual Disabilities*, *25*(1), 71–79. https://doi.org/10.1111/j.1468-3148.2011.00646.x	This article recruited 55 women with ID to complete a semi-structured interview about perceived control over their lives. Results found that women with ID have a perceived lack of control in their lives & need to be supplied the opportunity to participate in decisions about their life choices.
27	Tilford, J. M., Payakachat, N., Kovacs, E., Pyne, J. M., Brouwer, W., Nick, T. G., & Kuhlthau, K. A. (2012). Preference-based health-related quality-of-life outcomes in children with autism spectrum disorders. *Pharmacoeconomics*, *30*(8), 661-679. https://doi.org/10.2165/11597200-000000000-00000	This cross-sectional study evaluated HRQOL outcomes in children with ASDs & compared the sensitivity of two generic preference-based instruments compared to ASD related conditions & symptoms.
28	Townsend-White, C., Pham, A.N.T. & Vassos, M.V. (2012). A systematic review of quality of life measures for people with intellectual disabilities and challenging behaviors. *Journal of Intellectual Disability Research*, *56*(3), 270-284. https://doi.org/10.1111/j.1365-2788.2011.01427.x	This study conducted a systematic review of available QOL measures for people with ID to pinpoint psychometrically sound measures that can be routinely used for service evaluation. Results discovered that more instruments to measure QOL need to be developed & validated to be considered useful for this population.

29	Van Loon, J., Claes, C., & Schalock, R. (2012). The influence of environmental factors, personal characteristics and supports strategies on QOL-related personal outcomes. In 14th World Congress (IASSID-2012) (56) 7-8. https://doi.org/10.1016/j.ridd.2011.08.024	This study gathered data from 186 individuals with an ID. Results determined the role that available support strategies, environmental factors, & client characteristics played in assessed QOL related personal outcomes. All these factors significantly impacted QOL related personal outcomes.
30	Verdugo, M., Navas, P., Gómez, L. & Schalock, R. (2012). The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research*, *56*(11), 1036-1045. https://doi.org/10.1111/j.1365-2788.2012.01585.x	This article analyzed QOL-related outcomes and identified three strategies that can be used to enhance human rights of individuals with ID: person-centered planning, publishing provider profiles, and implementing a system of support.
31	Yoong, A., & Koritsas, S. (2012). The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research, 56*(6), 609-619. https://doi.org/10.1111/j.1365-2788.2011.01501.x	This study interviewed 12 parents who were full-time caregivers of adults with ID and further determined that caring for an adult with ID has both positive & negative impacts on their parents' QOL.

	2013	**Summary of Work**
1	Balboni, G., Coscarelli, A., Giunti, G., & Schalock, R. L. (2013). The assessment of the quality of life of adults with intellectual disability: The use of self-report and report of others assessment strategies. *Research in Developmental Disabilities, 34*(11), 4248-4254. https://doi.org/10.1016/j.ridd.2013.09.009	QOL of 176 adults with ID evaluated using the *Personal Outcomes* Scale. Reports showed that estimation of the client's point of view & self-report may be valid & reliable when clients are unable to answer.
2	Baum, N. (2013). The impact of practicing principles of quality and family quality of life on the personal growth, social knowledge and cognitive development of children and adults with intellectual/developmental disability. *International Journal of Child Health and Human Development*, *6*(4), 387. https://www.proquest.com/docview/1625518865?paren	QOL principles within a family of a person with IDD were researched on the effects they may have on the emotional, psychological, cognitive & language development of the person with IDD.
3	Bergström, H., Hochwälder, J., Kottorp, A. & Elinder, L. (2013). Psychometric evaluation of a scale to assess satisfaction with life among people with intellectual disabilities living in community residences. *Journal of Intellectual Disability Research*, *57*(3), 250-256. https://doi.org/10.1111/j.1365-2788.2011.01531.x	Satisfaction with home environment & leisure time in 132 adults with moderate or mild ID using a psychometric evaluation scale showed that the scale has good psychometric properties. Results can be seen as useful in further intervention studies.
4	Brown, I., Hatton, C., & Emerson, E. (2013). Quality of life indicators for individuals with intellectual disabilities: Extending current practice. *Intellectual and Developmental Disabilities, 51*(5), 316. https://doi.org/10.1352/1934-9556-51.5.316	A case is made for QOL frameworks & how they should be supplemented into evaluating policies & service practices. Case argues how a pragmatic approach should be taken to policy & program evaluation.
5	Chow, M. Y., Morrow, A. M., Robbins, S. C., & Leask, J. (2013). Condition-specific quality of life questionnaires for caregivers of children with pediatric conditions: A systematic review. *Quality of Life Research, 22*(8), 2183-2200. https://doi.org/10.1007/s11136-012-0343-z	QOL of condition-specific caregivers (n = 25) of children with illness or disability was studied using a variety of databases to extract questionnaires. Results highlighted how with an increase in questionnaires, there is improved recognition of caregiver QOL.
6	Claes, C., Vandevelde, S., Van Hove, G., Van Loon, J., Verschelden, G. & Schalock, R. (2012). Relationship between self-report and proxy ratings on assessed personal quality of life-related outcomes. *Journal of Policy and Practice in Intellectual Disabilities, 9*(3), 159-165. https://doi.org/10.1111/j.1741-1130.2012.00353.x	The impact of QOL scores of self-reports versus proxy ratings were evaluated using the Personal Outcomes Scale on individuals & family members of with ID. The difference between these two groups indicated that more needs to be done for individuals who cannot self-report.
7	Cummins, R., & Theofilou, P. (2013). Quality of life research: Interview with Professor Robert Cummins. *Health Psychology Research*, *1*(3), 31. https://doi.org/10.4081/hpr.2013.e31	Cummins discussed the importance of HRQOL concerning an individual's overall health, including physical or psychological factors that can be affected. Factors include physical & mental health cognitions like sexual functioning, sleep disorders & sociodemographic factors.
8	Giné, C., Vilaseca, R., Gràcia, M., Mora, J., Orcasitas, J. R., Simón, C, Simó-Pinatella, D. (2013). Spanish family quality of life scales: Under and over 18 years old. *Journal of Intellectual*	FQOL of 1205 Spanish families of adults with ID studied examined using two different measurement tools & two different diagnostic instruments. Results

	and Developmental Disability, 38(2), 141-148. https://doi.org/10.3109/13668250.2013.774324	found that the diagnostic tools have a purpose for changing the families' lives.
9	Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(11), 2604-2616. https://doi.org/10.1007/s10803-013-1812-0	Survey of 101 couples raising a child with ASD (autism spectrum disorder) regarding respite care, marital quality, & daily hassles indicated that an increase in respite care relieved stress, marital quality & daily hassles in families.
10	Hobden, K., Samuel, P., LeRoy, B., & Lindsay, D. (2013). An empirical examination of the prevalence and predictors of polypharmacy in individuals with dual diagnoses. *International Journal of Disability, Community and Rehabilitation*, *12*(1). https://www.ucalgary.ca/uofc/Others/ijdcr/VOL12_01/articles/hobden.shtml https://www.researchgate.net/publication/261062157_An_empirical_examination_of_the_prevalence_and_predictors_of_polypharmacy_in_individuals_with_dual_diagnoses	Retrospective chart review of 231 adults with ID in Southeast Michigan, USA was conducted to test the hypothesis that individuals with co-occurring psychiatric disorders or dual diagnoses would be at greater risk for polypharmacy than those with an ID only. Prevalence of polypharmacy was high with 45% of participants taking two or more psychotropic medications. Regression analysis indicated that having a dual diagnosis significantly predicted polypharmacy (β = 0.50), as did age (β = -0.11) & having a guardian (β = 0.16) accounting for 32% of the variance in the model specified to identify the predictors of polypharmacy.
11	Kamio, Y., Inada, N., & Koyama, T. (2013). A nationwide survey on quality of life and associated factors of adults with high-functioning autism spectrum disorders [HFSAD]. *Autism, 17*(1), 15-26. https://doi.org/10.1177/1362361312436848	Self-reported psychosocial QOL & associated factors in 154 adults with HFASD was analyzed. Results indicated that psychosocial QOL was lower for the Japanese adult population. Certain environmental factors were associated with better QOL.
12	Kose, S., Erermis, S., Ozturk, O., Ozbaran, B., Demiral, N., Bildik, T., & Aydin, C. (2013). Health related quality of life in children with autism spectrum disorders: The clinical and demographic related factors in Turkey. *Research in Autism Spectrum Disorders*, *7*(2), 213-220. https://doi.org/10.1016/j.rasd.2012.09.009	This study focused on the HRQOL of 102 children with autism (46 with autism, 38 with PDD-NOS & 18 with Asperger's syndrome and 39 typically developing children as a control), ages 3 to 18 years. Data was gathered from their mothers using the Pediatric QOL inventory. Results showed scores of physical & psychosocial health being lower in the ASD group than their typically developing peers.
13	Li, C., Tsoi, E. W. S., Zhang, A. L., Chen, S., & Wang, C. K. J. (2013). Psychometric properties of self-reported quality of life measures for people with intellectual disabilities: A systematic review. *Journal of Developmental and Physical Disabilities*, *25*(2), 253-270. https://doi.org/10.1007/s10882-012-9297-x	Outcome measure instruments from five databases of self-report measures of QOL in people with ID were examined with specific criteria. Results found that nine instruments met the criteria needed for future studies.
14	McStay, R. L., Dissanayake, C., Scheeren, A., Koot, H. M., & Begeer, S. (2013). Parenting stress and autism: The role of age, autism severity, quality of life and problem behavior of children and adolescents with autism. *Autism*, https://doi.org/10.1177/1362361313485163	The difference between parenting stress & general stress measured in 150 parents of children with ASD and neurotypical children. Results revealed that child hyperactivity is a factor in the increased stress of a parent with a child with ASD over other child characteristics.

15	Meral, B. F., Cavkaytar, A., Turnbull, A. P., & Wang, M. (2013). Family quality of life of Turkish families who have children with intellectual disabilities and autism. *Research and Practice for Persons with Severe Disabilities*, *38*(4), 233-246. https://eric.ed.gov/?id=EJ1049726	QOL of 3009 Turkish families of children with ID & ASD were examined, using three different scales including the Beach Center FQOLS. Results showed a moderate level of FQOL with highest scores in family interaction.
16	Pollard, C. A., Barry, C. M., Freedman, B. H., & Kotchick, B. A. (2013). Relationship quality as a moderator of anxiety in siblings of children diagnosed with autism spectrum disorders or Down syndrome. *Journal of Child and Family Studies*, *22*(5), 647-657. https://doi.org/10.1007/s10826-012-9618-9	The quality of relationships between people 119 with ASD & Down syndrome with their typically developing siblings was examined through an online survey. Results indicated that sibling relationships of those with Down syndrome were better than those with ASD.
17	Rey, L., Extremera, N., Durán, A., & Ortiz-Tallo, M. (2013). Subjective quality of life of people with intellectual disabilities: The role of emotional competence on their subjective well-being. *Journal of Applied Research in Intellectual Disabilities*, *26*(2), 146-156. https://doi.org/10.1111/jar.12015	Cross sectional study of the influence of person-related psychological resources on subjective well-being of 139 adults with ID showed that emotional competence is positively associated with life satisfaction & happiness.
18	Schalock, R. L., & Alonso, M. (2013). *The impact of the quality of life concept on the field of intellectual.* The Oxford Handbook of Positive Psychology and Disability, 37. https://books.google.com/books?hl=en&lr=	This chapter focuses on five impacts that the QOL concept has on an individual with IDDs. The QOL concept, paradigm, & the five impacts' influence on organization policies & practices in persons with IDD were discussed.
19	Tekinarslan, I. C. (2013). A comparison study of depression and quality of life in Turkish mothers of children with Down syndrome, cerebral palsy, and autism spectrum disorder. *Psychological Reports, 112*(1), 266-287. https://doi.org/10.2466/21.02.15.pr0.112.1.266-287	Depression levels & QOL in 252 Turkish mothers of children with Down syndrome, CP, & ASD are compared using the QOL-BREF assessment instrument & the Beck Depression Inventory scale. Results found an increase in education & income, while a decrease in depression for mothers.
20	Van Loon, J. H., Bonham, G. S., Peterson, D. D., Schalock, R. L., Claes, C., & Decramer, A. E. (2013). The use of evidence-based outcomes in systems and organizations providing services and supports to persons with intellectual disability. *Evaluation and Program Planning*, *36*(1), 80-87. https://doi.org/10.1016/j.evalprogplan.2012.08.002	A 5-component evidence-based outcomes model was used to improve clinical, managerial, & policy decisions using three international examples based on the reliable, valid & standardized assessment of individual QOL outcomes. Results found how EBOs can improve these outcomes.
21	Yang, H., Tai, Y., Yang, L., & Gau, S. S. (2013). Prediction of childhood ADHD symptoms to quality of life in young adults: Adult ADHD and anxiety/depression as mediators. *Research in Developmental Disabilities, 34*(10), 3168-3181. https://doi.org/10.1016/j.ridd.2013.06.011	ADHD symptoms were examined along with anxiety & depression & whether it mediates the association between childhood ADHD & QOL. Study used survey data gathered from 1,382 young men. Results found that there is a strong relationship between ADHD & QOL as an adult.
22	Zablotsky, B., Anderson, C., & Law, P. (2013). The association between child autism symptomatology, maternal quality of life, and risk for depression. *Journal of Autism and Developmental Disorders*, *43*(8), 1946-1955. https://doi.org/10.1007/s10803-012-1745-z	High levels of stress & a lower QOL was observed in mothers with children with ASD (N = 1,110). The association between the two findings indicated an increased risk for maternal depression & lower QOL in mothers with children of higher ASD symptomology.

	2014	**Summary of Work**
1	Baghdadli, A., Pry, R., Michelon, C., & Rattaz, C. (2014). Impact of autism in adolescents on parental quality of life. *Quality of Life Research, 23*(6), 1859-1868. https://doi.org/10.1007/s11136-014-0635-6	The impact of ASD in adolescents on parental QOL was analyzed using data gathered from 152 mothers using the parental-developmental disorders QOL scale. Results found that there was an increase in aberrant behavior scores as the major risk factor for parental QOL.
2	Barneveld, P. S., Swaab, H., Fagel, S., Engeland, H. V., & Sonneville, L. M. (2014). Quality of life: A case-controlled long-term follow-up study, comparing young high-functioning adults with autism spectrum disorders with adults with other psychiatric disorders diagnosed in childhood. *Comprehensive Psychiatry, 55*(2), 302-310. https://doi.org/10.1016/j.comppsych.2013.08.001	Long term outcome in childhood ASD disorders into adulthood examined in 169 high functioning adults & their QOL in comparison to other child psychiatric disorders was evaluated. Results indicate QOL was more compromised in adults with ASD in childhood than in adults with psychiatric disorders in childhood.
3	Benen Demchick, B., Goldrich Eskow, K., & Crabtree, L. A. (2014). Autism and transitioning youth: A pilot study of sensory processing and family quality of life. *Journal of Occupational Therapy, Schools, & Early Intervention*, *7*(1), 54-69. https://doi.org/10.1080/19411243.2014.898492	This pilot study explored sensory processing in 10 transition-aged youth (18-23 years) substantially impacted by autism and investigated the influence of sensory processing difficulties (evaluated using Adolescent/Adult Sensory Profile) on FQOL family quality of life. Sensory processing difficulties persisted into early adulthood in most transition-aged young adults and their families adapted tight schedule and plan to manage the young adult's sensory issues. About half of young adult sensory response pattern displayed negative affect characteristics (distress, upset, fear, hostility, and irritability)
4	Bretherton, S. J., & McLean, L. A. (2014). Mediating effects of perceived control in the relationship between optimism and adjustment in parents of children with disabilities. *Journal of Developmental and Physical Disabilities, 26*(3), 357-369. https://doi.org/10.1007/s10882-014-9371-7	The potential mediating effects of perceived control of internal states in the optimism-adjustment relationship in 83 parents of children with disabilities was examined. Participants completed various scales. Results found that perceived control was to partially mediate the optimism-adjustment relationship.
5	Brown, R.I., Brown, I. (2014). Family Quality of Life. In: Michalos, A.C. (eds). *Encyclopedia of Quality of Life and Well-Being Research*. Springer, Dordrecht. https://doi.org/10.1007/978-94-007-0753-5_1006	This is reference work entry published in the book, describing Family quality of life, Quality of life, and Family.
6	Brown, I., & Schormans, A. F. (2014). Quality of life, children with intellectual and developmental disabilities, and maltreatment. *International Public Health Journal*, *6*(2), 185. https://www.proquest.com/docview/1625960355	Child maltreatment was addressed as it relates to QOL & children with IDD. Results found increased likelihood of its occurrence & the negative associations it can have on the child.
7	Brown, R., Faragher, R., Merrick, J. (2014). Intellectual disability and quality of life. *International Public Health Journal*, *6*(2), 87-89. https://www.proquest.com/docview/1625960501?parentSessionId	A QOL approach was used to deal with a perception regarding individual needs & required support. The approach provided a necessary platform in education, health & community to improve one's contribution to society.

8	Chiang, H. M., & Wineman, I. (2014). Factors associated with quality of life in individuals with autism spectrum disorders: A review of literature. *Research in Autism Spectrum Disorders*, *8*(8), 974-986. http://interactingwithautism.com/pdf/treating/38Chiang2014.pdf	The level of QOL in persons with ASD & the factors associated with their QOL in a review of 16 studies. Results found that QOL was poor in individuals with ASD. Behavior problems & leisure activities were associated with QOL; there were various contributions to the severity of ASD.
9	Dardas, L. A., & Ahmad, M. M. (2014). Quality of life among parents of children with autistic disorder: A sample from the Arab world. *Research in Developmental Disabilities, 35*(2), 278-287. https://doi.org/10.1016/j.ridd.2013.10.029	A self-administered questionnaire was given to 184 parents of children with ASD to measure their QOL, stress, coping strategies, & demographic characteristics. Results found that there were no significant differences between father & mother's physical, psychological, social & environmental health.
10	Delahaye, J., Kovacs, E., Sikora, D., Hall, T. A., Orlich, F., Clemons, T. E., & Kuhlthau, K. (2014). The relationship between health-related quality of life and sleep problems in children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *8*(3), 292-303. https://ohsu.pure.elsevier.com/en/publications/the-relationship-between-health-related-quality-of-life-and-sleep	The relationship between sleep disturbance & HRQOL was explored in 86 parents of children with ASD, using a proxy-report on their children's sleeping habits. Results found that there is a negative relationship between sleep disturbance & HRQOL in children.
11	Dhas, B., Samuel P. S., Chockalingam M. (2014). Computer access technology as an alternative to writing for a pre-schooler with athetoid cerebral palsy – A case report. *Occupational Therapy in Health Care, 28*(3), 318-32. https://doi.org/10.3109/07380577.2013.874063	The use of computer access technology for a preschool child with athetoid CP was used to demonstrate the use of an outcome-driven model of decision-making. The model can explore the use of a CAT device in enabling the preschoolers' written communication skills.
12	Diken, Ö. (2014). Pragmatic language skills of children with developmental disabilities: A descriptive and relational study in Turkey. *Eurasian Journal of Educational Research*, (55), 109. https://files.eric.ed.gov/fulltext/EJ1060455.pdf	The pragmatic language skills of 34 children with ASD & 52 children with ID were examined using a Turkish version of the Gilliam Autism Rating Scale 2 & the Pragmatic Language Skills Inventory. Results found that most participants indicated poor pragmatic language skills.
13	Eapen, V., Črnčec, R., Walter, A., & Tay, K. P. (2014). Conceptualization and development of a quality of life measure for parents of children with autism spectrum disorder. *Autism Research and Treatment.* https://doi.org/10.1155/2014/160783	QOL in children with ASD were examined using the QOL in Autism Questionnaire with parents of 39 children in families. Results found that QOL-A has excellent consistency as well as validity; it is seen as a valuable assessment tool.
14	Emerson, E., & Families Special Interest Research Group of IASSIDD. (2014). Families supporting a child with intellectual or developmental disabilities: The current state of knowledge. *Journal of Applied Research in Intellectual Disabilities*, *27*(5), 420-430. https://doi.org/10.1111/jar.12078	This paper provided a summary of existing scientific knowledge regarding the situation, challenges, & wellbeing of families that have a child with IDD. As well as priorities for future research within this topic.
15	Foley, K., Girdler, S., Downs, J., Jacoby, P., Bourke, J., Lennox, N., Leonard, H. (2014). Relationship between family quality of life and day occupations of young people with Down syndrome. *Social Psychiatry and Psychiatric Epidemiology, 49*(9), 1455-1465. https://doi.org/10.1007/s00127-013-0812-x	This study examined the relationship between FQOL, day occupations & ADL studied in 150 families young people with Down syndrome using the "Needs Opinions Wishes" database. It was found that families of young people attending open employment reported poorer FQOL (after adjusting for personal characteristics,

		behavior and income) when compared to families of young people in sheltered employment. Families of young people with greater functioning in ADL reported better FQOL regardless of personal & environmental factors & inclusion of family factors such as family supports that reduced this association.
16	Francis, G. L., Blue-Banning, M., & Turnbull, R. (2014). Variables within a household that Influence quality-of-life outcomes for individuals with intellectual and developmental disabilities living in the community discovering the gaps. *Research and Practice for Persons with Severe Disabilities, 39*(1), 3-10. https://doi.org/10.1177/1540796914534632	The key variables within a household that influence individual QOL for persons with IDD & their families in their community were examined. How they can make informed decisions about the housing options available to them was also examined.
17	Hoefman, R., Payakachat, N., van Exel, J., Kuhlthau, K., Kovacs, E., Pyne, J., & Tilford, J. M. (2014). Caring for a child with autism spectrum disorder and parents' quality of life: Application of the CarerQol. *Journal of Autism and Developmental Disorders, 44*(8), 1933-1945. https://doi.org/10.1007/s10803-014-2066-1	The impact of caregiving on parents of children with ASD was described as well as the construct validation of the care related QOL instrument. Results found that the CarerQol is valid as it measures the impact of caregiving for children with ASD.
18	Horovitz, M., Shear, S., Mancini, L. M., & Pellerito, V. M. (2014). The relationship between axis I psychopathology and quality of life in adults with mild to moderate intellectual disability. *Research in Developmental Disabilities*, *35*(1), 137-143. https://doi.org/10.1016/j.ridd.2013.10.014	An examination of the role that Axis 1 psychopathology plays in the QOL of 138 adults with moderate to borderline ID was studied in relation to the scores of the general population. Results found that those with no Axis 1 diagnosis had higher QOL-Q scores.
19	Ikeda, E., Hinckson, E., & Krägeloh, C. (2014). Assessment of quality of life in children and youth with autism spectrum disorder: A critical review. *Quality of Life Research*, *23*(4), 1069-1085. https://doi.org/10.1007/s11136-013-0591-6	The QOL measures utilized in children & youth with ASD were analyzed using various databases that were reviewed for research. Results found several QOL measures used in this population. The most common one was the Pediatric QOL Inventory.
20	Khanna, R., Jariwala-Parikh, K., West-Strum, D., & Mahabaleshwarkar, R. (2014). Health-related quality of life and its determinants among adults with autism. *Research in Autism Spectrum Disorders*, *8*(3), 157-167. https://doi.org/10.1016/j.rasd.2013.11.003	HRQOL in adults with ASD was compared with HRQOL in the general population, using a cross-sectional online survey to gather information from 291 adults. Results revealed that adults with ASD have significantly lower physical & mental HRQoL than the general population in the US.
21	Kuhlthau, K., Payakachat, N., Delahaye, J., Hurson, J., Pyne, J. M., Kovacs, E., & Tilford, J. M. (2014). Quality of life for parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *8*(10), 1339-1350. https://doi.org/10.1016/j.rasd.2014.07.002	HRQOL such as depression & caregiver burden of 224 parents of children with ASD was analyzed using a mixed method. Results found that HRQoL scores were slightly worse than the general population.
22	Lin, L. Y. (2014). Quality of life of Taiwanese adults with autism spectrum disorder. *PLOS One*, *9*(10), e109567. https://doi.org/10.1371/journal.pone.0109567	QOL scores among (n = 41) adults with ASD & (n = 41) adults without ASD were compared to using the Taiwanese version of the World Health Organization QOL-BREF. Results found that adults with ASD had significantly lower scores overall.
23	Mcstay, R. L., Trembath, D., & Dissanayake, C. (2014). Maternal stress and family quality of life in response to raising	The role of child age in maternal stress & family QOL in 140 mothers raising a child with ASD was analyzed using

	a child with autism: From preschool to adolescence. *Research in Developmental Disabilities, 35*(11), 3119-3130. https://doi.org/10.1016/j.ridd.2014.07.043	a cross-sectional design. They completed questionnaires, revealing that there were no significant age effects that contribute to maternal stress.
24	Pozo, Sarriá, E., & Brioso, A. (2014). Family quality of life and psychological well-being in parents of children with autism spectrum disorders: A double ABCX model. *Journal of Intellectual Disability Research, 58*(5), 442-458. https://doi.org/10.1111/jir.12042	Family QOL & psychological well-being from a multidimensional perspective was analyzed, using 180 parents with a child that is diagnosed with ASD. Separate path analysis evaluated models of FQOL & psychological well-being. Results found that the severity of the disorder & social support played a role in their FQOL.
25	Reinders, H. S., & Schalock, R. L. (2014). How organizations can enhance the quality of life of their clients and assess their results: The concept of QOL enhancement. *American Journal on Intellectual and Developmental Disabilities, 119*(4), 291-302. https://doi.org/10.1352/1944-7558-119.4.291	A dynamic approach framework to QOL summarized the premises of QOL enhancement, provided rationale for a dynamic approach to QOL enhancement, provided rationale for this, discussed the 6 components of QOL enhancement, & discussed parameters of an emerging theory of QOL for overall QOL research.
26	Schalock, R. L. (2014). Quality of life as a change agent. *International Public Health Journal, 6*(2), 105. https://www.proquest.com/docview/1625960384?pq-origsite=gscholar&fromopenview=true	This paper described how the QOL concept has influenced policies & practices within the field & become a framework for organization & systems. Results concluded a discussion of 9 implementation guidelines.
27	Schalock, R. L., Lee, T., Verdugo, M., Swart, K., Claes, C., van Loon, J., & Lee, C. S. (2014). An evidence-based approach to organization, evaluation, and change in human service organizations evaluation and program planning. *Evaluation and Program Planning, 45*, 110-118. https://doi.org/10.1016/j.evalprogplan.2014.03.012	Human service organizations were discussed & how they used evidence-based, self-assessment approach to organization evaluation to facilitate continuous quality improvement & organization change using real-life examples.
28	Smith, L. E., Greenberg J. S., & Mailick, M. R. (2014). The family context of autism spectrum disorders: Influence on the behavioral phenotype and quality of life. *Child and Adolescent Psychiatric Clinics*, *23*(1), 143-155. https://doi.org/10.1016/j.chc.2013.08.006	A longitudinal program of research was used to report findings of bidirectional influence of the family environment on the behavioral phenotype of ASD. Results described a new program called Transitioning Together, which can overall improve the QOL in families of children with ASD.
29	Tobin, M. C., Drager, K. D., & Richardson, L. F. (2014). A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life. *Research in Autism Spectrum Disorders, 8*(3), 214-229. https://doi.org/10.1016/j.rasd.2013.12.002	Support for social participation for adults with ASD was reviewed, using a database search that evaluated 14 studies. Results found that social participation, social functioning & QOL for adults with ASD do have support.
30	Tung, L. C., Huang, C. Y., Tseng, M. H., Yen, H. C., Tsai, Y. P., Lin, Y. C., & Chen, K. L. (2014). Correlates of health-related quality of life and the perception of its importance in caregivers of children with autism. *Research in Autism Spectrum Disorders*, *8*(9), 1235-1242. https://doi.org/10.1016/j.rasd.2014.06.010	This study investigated the correlation of HRQOL & perceptions of the importance of each HRQOL domain in caregivers of children with ASD. Results revealed that the severity of ASD, behavior problems, & parenting stress individually had low to moderate associations with HRQOL.
31	Van Heijst, B. F., & Geurts, H. M. (2014). Quality of life in autism across the lifespan: A meta-analysis. *Autism,* https://doi.org/10.1177/1362361313517053	A meta-analysis included 10 studies with 486 participants with ASD & 17,776 controls was done to understand the effect of age on QOL. Results found that QOL is lower for people with ASD compared to people without ASD.

32	Van Loon, J. H. M., Claes, C., Vandevelde, S., & Schalock, R. L. (2014). Crossing boundaries; QOL assessment in 6 countries using the Personal Outcomes Scale (POS). *Journal of Applied Research in Intellectual Disabilities*, *27*(4), 344-344. https://lib.ugent.be/catalog/pug01:7087155	This presentation summarized key challenges related to people with ID living in the community in Australia & UK, pulling together current policy & practice implications.
33	Williamson, H., & Perkins, E. (2014). Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with US services and supports. *Intellectual and Developmental Disabilities, 52*(2), 147-159. https://doi.org/10.1352/1934-9556-52.2.147	A literature review conducted to identify U.S family caregiver outcomes & their association with existing services & supports for family caregivers of adults with IDD. Close examination of 24 articles indicated the need for comprehensive caregiver assessment.
34	Yashoda, R., & Puranik, M. P. (2014). Oral health status and parental perception of child oral health related quality-of-life of children with autism in Bangalore, India. *Journal of Indian Society of Pedodontics and Preventive Dentistry*, *32*(2), 135. https://doi.org/10.5005%2Fjp-journals-10005-1972	The oral health status & parental cross-sectional study was conducted in 135 children with ASD & 135 children without ASD. The Oral Hygiene Index-Simplified was used to collect data. Results revealed DMFT scores being high among children with ASD.
35	Zuna, N. I., Brown, I., & Brown, R. I. (2014). Family quality of life in intellectual and developmental disabilities: A support-based framework. *International Public Health Journal*, *6*(2), 161. https://www.proquest.com/docview/1625960329	The integration of family support & family QOL was examined & how it can work to help improve family outcomes. This journal focused on FQOL support-based framework.

	2015	**Summary of Work**
1	Asselt-Goverts, A. E., Embregts, P. J. C. M., & Hendriks, A. H. C. (2015). Social networks of people with mild intellectual disabilities: Characteristics, satisfaction, wishes and quality of life. *Journal of Intellectual Disability Research*, *59*(5), 450-461. https://doi.org/10.1111/jir.12143	How people with mind ID perceive their social networks & which network characteristics relate to satisfaction in (n = 33) young adults with mild ID was investigated, using structured questionnaires. Results found that most participants were satisfied with their social networks.
2	Bazzano, A., Wolfe, C., Zylowska, L., Wang, S., Schuster, E., Barrett, C., Lehrer, D. (2015). Mindfulness based stress reduction (MBSR) for parents and caregivers of individuals with developmental disabilities: A community-based approach. *Journal of Child and Family Studies*, *24*(2), 298-308. https://doi.org/10.1007/s10826-013-9836-9	The needs of (n = 66) parents or caregivers of children with DDs was studied using a mindfulness-based stress reduction program in a community-based participatory setting. Results found that there was a significant reduction in perceived stress.
3	Blick, R. N., Saad, A. E., Goreczny, A. J., Roman, K., & Sorensen, C. H. (2015). Effects of declared levels of physical activity on quality of life of individuals with intellectual disabilities. *Research in Developmental Disabilities*, *37*, 223-229. https://doi.org/10.1016/j.ridd.2014.11.021	The impact of physical fitness on QOL was compared to individuals who maintain a physically active lifestyle with those who do not. Results reported that individuals who exercise regularly have more community outings than those who do not.
4	Boehm, Thomas L., Carter, Erik W., Taylor, Julie L. (2015) Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities, 120*(5), 395-411. https://doi.org/10.1352/1944-7558-120.5.395	FQOL among families with transition-age youth & young adults were examined in (N = 425) parents who have a child with ID or ASD. This sample's rating indicated they were high satisfaction with FQOL.
5	Boehm, T., Carter, E., & Taylor, J. (2015). Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *Ajidd-American Journal on Intellectual and Developmental Disabilities*, *120*(5), 395-411. https://doi.org/10.1352/1944-7558-120.5.395	FQOL in families with transition-age youth & young adults are examined in 425 parents with a child with ID or ASD. Results found that there was high satisfaction with FQOL ratings.
6	Clark, B. G., Magill-Evans, J. E., & Koning, C. J. (2015). Youth with autism spectrum disorders: Self-and proxy-reported quality of life and adaptive functioning. *Focus on Autism and Other Developmental Disabilities*, *30*(1), 57-64. https://doi.org/10.1177/1088357614522289	The QOL in adolescents (n = 22) with ASD was explored as they completed 10 subscales of the KIDSCREEN-52 standardized questionnaire with their parents, completing the Adaptive Behavior Assessment System-II. Results found that both groups reported mean QOL scores in the lower average range.
7	Cummins, R. A., & Weinberg, M. K. (2015). Multi-item measurement of subjective wellbeing: Subjective approaches (2). In W.Glatzer, L. Camfield, V. Møller, M. Rojas (eds). *Global Handbook of Quality of Life*, 239-268. International Handbooks of Quality-of-Life. Springer, Dordrecht. https://doi.org/10.1007/978-94-017-9178-6_10 https://link.springer.com/chapter/10.1007/978-94-017-9178-6_10	A theoretical view of subjective wellbeing & an evaluation of subjective wellbeing was explored in this chapter. Reports found that no scale with this simple construction can reliably support more than one factor.
8	Dardas, L. A., & Ahmad, M. M. (2015). For fathers raising children with autism, do coping strategies mediate or moderate the relationship between parenting stress and	The mediation & moderation effects of coping with fathers of children with ASD parenting stress & QOL was examined using (N = 101) fathers using multiple

	quality of life? *Research in Developmental Disabilities, 36*, 620-629. https://doi.org/10.1016/j.ridd.2014.10.047	programs & software. Results found that the relationship can be affected by the nature of their stressful situation, their individual characteristics, perception & environmental factors.
9	De Vries, M., & Geurts, H. (2015). Influence of autism traits and executive functioning on quality of life in children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *45*(9), 2734-2743. https://doi.org/10.1007/s10803-015-2438-1	Early language development, IQ, current ASD traits, daily executive functions, & QOL in (N = 120) children with ASD were analyzed. Reports found that children with ASD showed a lower QOL than typically developing children.
10	Giné, C., Gràcia, M., Vilaseca, R., Salvador Beltran, F., Balcells-Balcells, A., Montalà, D. M., Alcocer, A. L. A., Pro, M. T., Simó-Pinatella, D., Mestre, J. M. M. (2015). Family quality of life for people with intellectual disabilities in Catalonia. *Journal of Policy and Practice in Intellectual Disabilities*, *12*(4), 244-254. https://doi.org/10.1111/jppi.12134	FQOL was explored in (N = 266) families who used the Spanish FQOL Scales. Results indicated that FQOL is higher in families with adult children over 18 years old; differences among domains in both groups were present.
11	Gómez, L. E., Arias, B., Verdugo, M. Á., Tassé, M. J., & Brown, I. (2015). Operationalization of quality of life for adults with severe disabilities. *Journal of Intellectual Disability Research*. https://doi.org/10.1111/jir.12204	QOL of adults with severe disabilities was studied using Delphi method, including 12 experts who used descriptive analysis to select the best items for the Delphi study. Results found that best items were related to material well-being; the weakest were found for items relating to personal development.
12	Heller, T., Gibbons, H., & Fisher, D. (2015). Caregiving and family support interventions: Crossing networks of aging and developmental disabilities. *Intellectual and Developmental Disabilities*, *53*(5), 329-345. https://doi.org/10.1352/1934-9556-53.5.329	69 studies were reviewed to address 5 questions on caregiving & family support interventions. Results found that family-support interventions helped participants' well-being & improved service access & satisfaction.
13	Jaschke, A. C., & Scherder, E. J. (2015). Music intervention, agitation, quality of life and repetitive behavior in people with a form of intellectual disability: A brief pilot report. *Journal of Neurology and Neuroscience*, *06*, Article s1. https://doi.org/10.21767/2171-6625.s10006	Survey data from 112 participants to find out if structured music interventions influenced agitation, repetitive behaviors, and QOL (measured by Intellectual Disability Quality of Life-16). Findings indicate that (1) music is hardly offered in a structured manner to improve behavior and (2) agitation & behavioral problems were very low in the tested sample in Netherlands.
13	Juhásová, A. (2015). Comparison of quality of Life of families with children with disability and families with children without disability. *Procedia - Social and Behavioral Sciences*, *174*, 3378-3384. https://doi.org/10.1016/j.sbspro.2015.01.1007	The paper focuses on the QOL of 100 families of children with disabilities, and the site of psychological, physical, social and environmental performance compared to families with a child without disabilities. The environment was the biggest difference in the QOL among families in this survey research study.
14	Lensing, M., Zeiner, P., Sandvik, L., & Opjordsmoen, S. (2015). Quality of life in adults aged 50 with ADHD. *Journal of Attention Disorders, 19*(5), 405-413. https://doi.org/10.1177/1087054713480035	The QOL in 148 adults with ADHD was studied using an EuroQol & the Satisfaction with Life Scale. Results found that adults with ADHD reported significantly reduced HRQOL & satisfaction with life compared to normal population.

15	Li, A., Shaffer, J., & Bagger, J. (2015). The psychological well-being of disability caregivers: Examining the roles of family strain, family-to-work conflict, and perceived supervisor support. *Journal of Occupational Health Psychology*, *20*(1), 40-49. https://doi.org/10.1037/a0037878	The relationship between disability caregiving demands & the psychological well-being of employed caregivers was analyzed using the cross-domain of work-family conflict & conservation of resources theory. Results found that the relationship between caregiving demands & family to-work conflict was associated with decreases in life satisfaction & an increase in depression.
16	Lin, Y., Lo, K., Yang, L., & Gau, S. (2015). Validation of DSM-5 age-of-onset criterion of attention deficit/hyperactivity disorder (ADHD) in adults: Comparison of life quality, functional impairment, and family function. *Research in Developmental Disabilities*, *47*, 48-60. https://doi.org/10.1016/j.ridd.2015.07.026	QOL & functional impairment of adults with ADHD who have symptoms of anxiety & depression was examined in 189 adults with ADHD & 153 adults without ADHD using a psychiatric interview & various self-report scale. Results found that there was a decrease in QOL & increase in functional impairment in adult ADHD regardless of onset.
17	Long, K., Kao, B., Plante, W., Seifer, R., & Lobato, D. (2015). Cultural and child-related predictors of distress among latina caregivers of children with intellectual disabilities. *Ajidd-American Journal on Intellectual and Developmental Disabilities*, *120*(2), 145-165. https://doi.org/10.1352/1944-7558-120.2.145	The associations among socioeconomic, cultural, child factors & maternal distress among families of 192 children with ID was examined in Latina caregivers. Results reported that child & cultural factors can contribute to elevated distress in Latina mothers of children with ID.
18	Meadan, H., Stoner, J. B., & Angell, M. E. (2015). Fathers of children with autism: Perceived roles, responsibilities, and support needs. *Early Child Development and Care*, *185*(10), 1678-1694. https://doi.org/10.1080/03004430.2015.1019876	The experiences & roles of fathers of children with disabilities was examined using seven fathers of children with ASD, using an interview about their perceived roles & responsibilities.
19	Park, H., & Chung, G. (2015; 2014). A multifaceted model of changes and adaptation among Korean mothers of children with disabilities. *Journal of Child and Family Studies*, *24*(4), 915-929. https://doi.org/10.1007/s10826-014-9902-y	This study examined a dynamic process of change among mothers raising children with disabilities overtime. Participants included 18 Korean mothers to better understand their society. Results found that an intervention program should be held to public policy in a greater sense.
20	Pedersen, A., Crnic, K., Baker, B., & Blacher, J. (2015). Reconceptualizing family adaptation to developmental delay. *Ajidd-American Journal on Intellectual and Developmental Disabilities*, *120*(4), 346-370. https://doi.org/10.1352/1944-7558-120.4.346	Accurate conceptualization of the adaptation construct in families of children with developmental delay was examined using self-report measures from the parents of adaptation. Results showed that adaptational processes vary across adaptation index, child developmental level, & parent gender.
21	Perry, A., & Isaacs, B. (2015). Validity of the Family Quality of Life Survey-2006. *Journal of Applied Research in Intellectual Disabilities*. https://doi.org/10.1111/jar.12141	The psychometric properties of the Family QOL Survey-2006 was examined by its concurrent validity compared to the well-established Beach Center FQOL scale. Study included 62 children with ID or ASD. Results found that the two measures were strongly correlated.
22	Potvin, M. C., Snider, L., Prelock, P. A., Wood-Dauphinee, S., Kehayia, E. (2015). Health-related quality of life in children	A comparison in HRQOL with (n = 30) HF-ASD to (n = 31) typically developing peers was compared, using child-self & parent-proxy reports of HRQOL of

	with high-functioning autism. *Autism, 19*(1), 14-19. https://doi.org/10.1177/1362361313509730	children & Pediatric QOL Inventory 4.0 Generic Core scales. Results found that the research strengthened earlier findings.
23	Robert, M., Leblanc, L., & Boyer, T. (2015). When satisfaction is not directly related to the support services received: Understanding parents' varied experiences with specialized services for children with developmental disabilities. *British Journal of Learning Disabilities*, *43*(3), 168-177. https://doi.org/10.1111/bld.12092	Strengths & weaknesses in specialized support services of (n =15) parents & their well-being & satisfaction was analyzed. Parent's experiences identified the conditions & the perceptions in which feeling satisfied or unsatisfied was discussed.
24	Rossetti, Z., & Hall, S. (2015). Adult sibling relationships with brothers and sisters with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, *40*(2), 120-137. https://doi.org/10.1177/1540796915592829	This qualitative study examined perceptions of (n = 72) adult sibling-pairs relationships with a brother or sister with severe disabilities & the contexts affecting the relationships using an online survey of open-ended questions. Results found that more than half of the sibling-pairs reported being close relationships.
26	Schippers, A., Zuna, N., & Brown, I. (2015). A proposed framework for an integrated process of improving quality of life. *Journal of Policy and Practice in Intellectual Disabilities.* https://doi.org/10.1111/jppi.12111	There is a clear need to use QOL as a concept and a measure in policy and practice. This paper discussed Schalock & Verdugo’s 2102 QOL model and recommends that QOL outcomes should be an ultimate focus of service organizations and policy development if QOL is to be enhanced for individuals with IDD & their families.
27	Simões, C., Santos, S., Claes, C. (2015). Quality of life assessment in intellectual disabilities: The Escala Pessoal de Resultados versus the World Health Quality of Life-BREF. *Research in Developmental Disabilities, 37*, 171-181. https://doi.org/10.1016/j.ridd.2014.11.010	The Escala Pessoal de Resultados & the World Health QOL-BREF in QOL assessment of people with IDs were compared using 216 adults with ID. Results revealed in both the scales having adequate reliability, construct, & discriminant validity.
28	Simplican, S., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, *38*, 18-29. https://doi.org/10.1016/j.ridd.2014.10.008	An ecological model of social inclusion that includes individual, interpersonal, organizational, community & socio-political factors was proposed. As well as four areas of research that the ecological model of social inclusion can be used to move forward.
29	Suzumura, S. (2015). Quality of life in mothers of preschoolers with high-functioning pervasive developmental disorders. *Pediatrics International*, *57*(1), 149-154. https://doi.org/10.1111/ped.12560	Distress among 30 mothers of preschoolers with high-functioning pervasive DDs was examined in relation to the child’s behavioral characteristics. This study used the Short-Form 36 Health Survey Questionnaire. Results found that mothers in the HFPDD group were more distressed both mentally & physically.
30	Tracy, J., & McDonald, R. (2015). Health and disability: Partnerships in health care. *Journal of Applied Research in Intellectual Disabilities*, *28*(1), 22-32. https://doi.org/10.1111/jar.12135	The health inequalities experienced by people with IDs was outlined as the focus on the opportunity's medical education. Results addressed these, concluding that improvements in health enhances QOL & enables engagement in social & economic life of communities.

31	Viecili, M., & Weiss, J. (2015). Reliability and validity of the pediatric quality of life inventory with individuals with intellectual and developmental disabilities. *Ajidd-American Journal on Intellectual and Developmental Disabilities*, *120*(4), 289-301. https://doi.org/10.1352/1944-7558-120.4.289	This study assessed the reliability & validity of the Pediatric QOL Inventory in 359 caregivers of individuals with IDD & ASD, finding that the PedsQL did achieve reliability.
32	Vilaseca, R., Gràcia, M., Beltran, F. S., Dalmau, M., Alomar, E., Adam-Alcocer, et al. (2015). Needs and supports of people with intellectual disability and their families in Catalonia. *Journal of Applied Research in Intellectual Disabilities.* https://doi.org/10.1111/jar.12215	The support needs of individuals with IDs & their (n = 2160) families was assessed along with their QOL. Perceptions of how much their family receives services were used. Results found that the FQOL was high. Many did not receive the support they needed.
33	Woodman, A. C., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2015). Change in autism symptoms and maladaptive behaviors in adolescence and adulthood: The role of positive family processes. *Journal of Autism and Developmental Disorders*, *45*(1), 111-126. https://doi.org/10.1007/s10803-014-2199-2	A prospective, longitudinal design was used in this study to describe & predict trajectories of ASD symptoms & maladaptive behaviors over 8.5 years in a large community-based sample of adolescents & adults with ASD. ASD symptoms & maladaptive behaviors improved over the study period.
34	Woodman, A., Mawdsley, H., & Hauser-Cram, P. (2015). Parenting stress and child behavior problems within families of children with developmental disabilities: Transactional relations across 15 years. *Research in Developmental Disabilities*, *36*, 264-276. https://doi.org/10.1016/j.ridd.2014.10.011	The transactional relations between child behavior problems & maternal stress within 176 families raising a child with early diagnosed DD was the focus of this study. Results found that there was evidence of both child & parent-driven effects consistent with transactional models of development in the 15-year study.

	2016	Summary of Work
1	Alshamri, K. H. (2016). Family quality of life for families of children with intellectual disability in Saudi Arabia. *UWS Research* https://researchdirect.westernsydney.edu.au/islandora/object/uws:40063	This thesis discussed the FQOL of children with IDs in Saudi Arabia. A questionnaire based on the Beach Center FQOL Scale, modified for Saudi Arabia, was administered to families (n = 201), & interviews were conducted with Saudi families (n = 8) as well. Results found that families with a child with ID reported a significantly lower QOL. Socio-economic status & marital status were the major factors affecting FQOL.
2	Bertelli, M. O., Bianco, A., Piva Merli, M., Scuticchio, D., Lassi, S., Lorenzoni, L.,Brown, I. (2016). Psychometric properties of the Italian adaptation of a quality of life instrument as applied to adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 13*(3), 227-235. https://doi.org/10.1111/jppi.12158	This study uses BASIQ to assess 281 adults with ID. Results found that the instrument had good internal consistency & satisfactory inter-rater reliability, concluding it is a valid instrument to assess QOL.
3	Bhopti, A., Brown, T., & Lentin, P. (2016). Family quality of life: A key outcome in early childhood intervention services a scoping review. *Journal of Early Intervention*, *38*(4), 191-211. https://doi.org/10.1177/10538151166731	A review of articles (N = 18) to identify factors influencing the QOL of families of children with disabilities. Results were summarized as five factors that affect FQOL (disability-related support, family relationships, overall well-being, support from services, & severity/type of disability).
4	Bigby, C., & Beadle-Brown, J. (2016). Improving quality of life outcomes in supported accommodation for people with intellectual disability: What makes a difference? *Journal of Applied Research in Intellectual Disabilities*. https://doi.org/10.1111/jar.12291	This article is a review of literature exposed to different variables influencing QOL outcomes. The evidence was strongest for the presence of staff practices, front-line management practice, culture, human resources policies & practice, adequate resources, & small, homelike settings.
5	Biggs, E. E., & Carter, E. W. (2016). Quality of life for transition-age youth with autism or intellectual disability. *Journal of Autism and Developmental Disorders*, *46*(1), 190-204. https://doi.org/10.1007/s10803-015-2563-x	This study examined the health & well-being of 389 youth with ASD or ID, using the parent proxy version of the Kidscreen-27. Results found that parents reported well-being of youth with ASD/ID lower than a normative sample.
6	Blick, Rachel N., Goreczny, Anthony J., Litz, Katherine S., Thornhill, Monica G. (2016). Do inclusive work environments matter? Effects of community-integrated employment on quality of life for individuals with intellectual disabilities, *Research in Developmental Disabilities, 53*, (Pg 358-366), ISSN 0891-4222, https://doi.org/10.1016/j.ridd.2016.02.015	This study used structured interviews to compare the QOL of community-integrated workers with those participating in adult day care programs (n = 477). Results revealed that participants involved in community-integrated employment tended to be younger, had greater sense of community integration, & reported more financial autonomy.
7	Boehm, T. L., & Carter, E. W. (2016). A systematic review of informal relationships among parents of individuals with intellectual disability or autism. *Research and Practice for Persons with Severe Disabilities*, *41*(3), 173-190. https://doi.org/10.1177/1540796916657	In this review, findings from 52 studies were summarized, addressing the informal relationships of parents & their association with a range of parent & family outcomes for future research. These efforts to improve the lives of parents of children with IDD were discussed.

8	Brown, R. I., & Schippers, A. (2016). Special issue: Quality of life and family quality of life: Recent developments in research and application. *Journal of Intellectual & Developmental Disability, 41*(4), 277-278. https://doi.org/10.3109/13668250.2016.1234958	This issue focuses on how QOL is seen as a lifespan topic both for individuals with IDD & their families. The article then argued that both QOL & FQOL contain fundamental aspects of social living & have relevance beyond IDD.
9	Faragher, R., & Van Ommen, M. (2016). Journal of policy and practice in intellectual disabilities: Conceptualising educational quality of life to understand the school experiences of students with intellectual disability. Blackwell Publishing. https://doi.org/10.1111/jppi.12213	This paper looked at different studies to explore QOL in the context of education for students with IDs. It conceptualized a new concept of QOL called EQOL (educational QOL).
10	Ferrer, F., Vilaseca, R., & Bersabé, R. M. (2016). The impact of demographic characteristics and the positive perceptions of parents on quality of life in families with a member with intellectual disability. *Journal of Developmental and Physical Disabilities*, 1-18. https://doi.org/10.1007/s10882-016-9515-z	This study analyzed the predictors of FQOL, while incorporating demographic variables & parents' perceptions before & after the family member with ID turns 18 (N = 861). Results found that families with positive perceptions reported higher levels of FQOL.
11	Heumen, L. V., & Schippers, A. (2016). Quality of life for young adults with intellectual disability following individualized support: Individual and family responses. J*ournal of Intellectual & Developmental Disability, 41*(4), 299-310. https://doi.org/10.3109/13668250.2016.1213797	This study evaluated the impact of a project in which families were individually supported in the realization of plans. The study used semi structured interviews with family members & adults with ID to find that most participants reported the project as positive.
12	Hsieh, R., Hsieh, W., & Lee, W. (2016). Short-term family-centered workshop for children with developmental delays enhances family functioning and satisfaction a prospective clinical trial. *Medicine*, *95*(31), e4200. https://doi.org/10.1097/MD.0000000000004200	This study investigated the efficacy & parental satisfaction of a short-term family-centered workshop for children with developmental delays (n = 32). The parents completed many assessments both before & after the workshop to note any significant improvements.
13	Jones, S., Bremer, E., & Lloyd, M. (2016). Autism spectrum disorder: Family quality of life while waiting for intervention services. *Quality of Life Research*, *26*(2), 331-342. https://doi.org/10.1007/s11136-016-1382-7	This study surveyed 454 families to determine how families of a child with ASD view their overall FQOL. Results found that the most influential factors were if the child had a major health concern, access to disability-related services, & opportunities to engage in leisure & recreation activities.
14	Jones, J. L., & Gallus, K. L. (2016). Understanding deinstitutionalization: What families value and desire in the transition to community living. *Research and Practice for Persons with Severe Disabilities*, *41*(2), 116-131. https://doi.org/10.1177/1540796916637050	This study conducted interviews with 23 families to better understand the lived experience of parents & siblings of individuals transitioning out of the North Oklahoma Resource Center Enid (NORCE)/South Oklahoma Resource Center (SORC) to community living.
15	Kyzar, K. B., Brady, S. E., Summers, J. A., Haines, S. J., & Turnbull, A. P. (2016). Services and supports, partnership,	This study examined the relationship between service adequacy & FQOL for families of children with deaf

	and family quality of life: Focus on deaf-blindness. *Exceptional Children*, *83*(1), 77-91. https://doi.org/10.1177/0014402916655432	blindness by conducting surveys with 227 families. Results found that FQOL can be explained by satisfaction with the adequacy of support & child-care services.
16	Jones, J. L., & Gallus, K. L. (2016). Understanding deinstitutionalization: What families value and desire in the transition to community living. *Research and Practice for Persons with Severe Disabilities*, *41*(2), 116-131. https://doi.org/10.1177/1540796916637050	This study conducted interviews with 23 families to better understand the lived experience of parents & siblings of individuals transitioning out of the North Oklahoma Resource Center Enid (NORCE)/South Oklahoma Resource Center (SORC) to community living.
17	Kyzar, K. B., Brady, S. E., Summers, J. A., Haines, S. J., & Turnbull, A. P. (2016). Services and supports, partnership, and family quality of life: Focus on deaf-blindness. *Exceptional Children*, *83*(1), 77-91. https://doi.org/10.1177/0014402916655432	This study examined the relationship between service adequacy & FQOL for families of children with deaf blindness by conducting surveys with 227 families. Results found that FQOL can be explained by satisfaction with the adequacy of support & child-care services.
18	Leonard, H., Foley, K., Pikora, T., Bourke, J., Wong, K., McPherson, L., Downs, J. (2016). Transition to adulthood for young people with intellectual disability: The experiences of their families. *European Child and Adolescent Psychiatry*, *25*(12), 1369-1381. https://doi.org/10.1007/s00787-016-0853-2	This study gave questionnaires to parents of young people with Down syndrome (n = 190) & young people with ID (n = 150). Results noted the themes that emerged, which included concerns about adapting to adulthood, navigating services, building connections, & finances.
19	Lindly, O., Chavez, A., & Zuckerman, K. (2016). Unmet health services needs among US children with developmental disabilities: Associations with family impact and child functioning. *Journal of Developmental and Behavioral Pediatrics*, *37*(9), 712-723. https://doi.org/10.1097/DBP.0000000000000363	This study was a secondary analysis of parent-reported data from a 2009–10 National Survey of Children with Special Healthcare Needs (n = 3,518). Results found that unmet needs are associated with adverse impacts for children with DD & their families. Increased access to health services may improve subsequent outcomes.
20	Lingen, M., Albers, L., Borchers, M., Haass, S., Gärtner, J., Schröder, S., Zirn, B. (2016). Obtaining a genetic diagnosis in a child with disability: Impact on parental quality of life. *Clinical Genetics*, *89*(2), 258-266. https://doi.org/10.1111/cge.12629	This study looks at the impact of a genetic diagnosis on parental QOL using a semiquantitative questionnaire with 99 families who have a child with a disability. Results found that a definite genetic diagnosis for a child with IDD improves maternal QOL substantially.
21	Luijkx, J., van der Putten, Annette A. J, & Vlaskamp, C. (2016). "I love my sister, but sometimes I don't": A qualitative study into the experiences of siblings of a child with profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability*, *41*(4), 279-288. https://doi.org/10.3109/13668250.2016.1224333	Photo elicitation interviews were conducted with 18 children who have a sibling with a PIMD. Results found that it influenced the children both positively & negatively. Shared activities with the sibling & private time are important for sibling QOL.
22	Marchal, J., Maurice-Stam, H., van Trotsenburg, A., & Grootenhuis, M. (2016). Mothers and fathers of young Dutch adolescents with Down syndrome: health related quality of life and family functioning. *Research in*	This study used HRQOL & family functioning questionnaires to determine whether mothers & fathers of children with Down syndrome differ from reference parents in HRQOL & family functioning.

	Developmental Disabilities, *59*, 359-369. https://doi.org/10.1016/j.ridd.2016.09.014	
23	Markowitz, L. A., Reyes, C., Embacher, R. A., Speer, L. L., Roizen, N., & Frazier, T. W. (2016). Development and psychometric evaluation of a psychosocial quality-of-life questionnaire for individuals with autism and related developmental disorders. *Autism*, *20*(7), 832-844. https://doi.org/10.1177/1362361315611382	Parents of children with ASD (N = 212) completed the Child & FQOL scale prior to diagnostic evaluation. Results found that caregivers of children with ASD reported reduced FQOL prior to diagnosis compared to caregivers of children with other DDs.
24	Mas, J. M., Baqués, N., Balcells-Balcells, A., Dalmau, M., Giné, C., Gràcia, M., & Vilaseca, R. (2016). Family quality of life for families in early intervention in Spain. *Journal of Early Intervention*, *38*(1), 59-74. https://doi.org/10.1177/1053815116636885	This study administered The FQOL Scale to 281 families with children attending an EI center. Results found that the perceived FQOL varied depending on income, family type, & severity of disability.
25	McKenzie, J., & McConkey, R. (2016). Caring for adults with intellectual disability: The perspectives of family carers in South Africa. *Journal of Applied Research in Intellectual Disabilities*, *29*(6), 531-541. https://doi.org/10.1111/jar.12209	This study analyzed focus group discussions with 37 family caregivers. Results found a sign of a strong commitment to care despite the burden they may experience. Many reported feeling let down by community services that are meant to assist them.
26	Nelson Goff, B. S., Monk, J. K., Malone, J., Staats, N., Tanner, A., & Springer, N. P. (2016). Comparing parents of children with Down Syndrome at different life span stages. *Journal of Marriage and Family*, *78*(4), 1131-1148. https://doi.org/10.1111/jomf.12312	This study explored the experiences of parents of children with Down syndrome through a survey given to 445 participants. Results found that parents reported higher coping strategy scores during the middle childhood & adolescent years than early childhood or later years.
27	O'Dea, Á., & Connell, A. (2016). Performance difficulties, activity limitations and participation restrictions of adolescents with developmental coordination disorder (DCD). *British Journal of Occupational Therapy*, *79*(9), 540-549. https://doi.org/10.1177/0308022616643100	This study used secondary analysis of 141 adolescents with dyspraxia to examine their performance difficulties, activity limitations, participation restrictions & health services needed. Results found that they experienced cognitive rather than physical impairments that affected participation. Access to OT (Occupational Therapists) & psychology is required.
28	Parpa, E., Katsantonis, N., Tsilika, E., Galanos, A., & Mystakidou, K. (2016). Psychometric properties of the family quality of life scale in Greek families with intellectual disabilities. *Journal of Developmental and Physical Disabilities*, *28*(3), 393-405. https://link.springer.com/article/10.1007/s10882-016-9477-1	This study examined 180 caregivers of people with IDs to examine the psychometric properties of the Greek version of FQOL. Results concluded that this version has satisfactory psychometric properties & is a valid research tool for Greek caregivers supporting people with IDs.
29.	Lee, Y. C., Yang, H. J., Chen, V. C. H., Lee, W. T., Teng, M. J., Lin, C. H., & Gossop, M. (2016). Meta-analysis of quality of life in children and adolescents with ADHD: By both parent proxy-report and child self-report using PedsQL™. *Research in Developmental Disabilities*, *51*, 160-172. https://doi.org/10.1016/j.ridd.2015.11.009	This study conducted a meta-analysis of 9 studies to examine the impact of ADHD on a child's health-related QOL through self-reports and parent proxy reports. Results indicated a negative impact of ADHD on HRQOL, especially in emotional domains.

30	Lindly, O., Chavez, A., & Zuckerman, K. (2016). Unmet health services needs among US children with developmental disabilities: Associations with family impact and child functioning. *Journal of Developmental and Behavioral Pediatrics*, *37*(9), 712-723. https://doi.org/10.1097/DBP.0000000000000363	Study was a secondary analysis of parent-reported data from a 2009–10 National Survey of Children with Special Healthcare Needs (n = 3,518). Results found that unmet needs are associated with adverse impacts for children with DD & their families. Increased access to health services may improve subsequent outcomes.
31	Lingen, M., Albers, L., Borchers, M., Haass, S., Gärtner, J., Schröder, S., Zirn, B. (2016). Obtaining a genetic diagnosis in a child with disability: Impact on parental quality of life. *Clinical Genetics*, *89*(2), 258-266. https://doi.org/10.1111/cge.12629	Study examined impact of a genetic diagnosis on parental QOL using questionnaire with 99 families who have a child with a disability. Results found that a definite genetic diagnosis for a child with IDD improves maternal QOL substantially.
32	Luijkx, J., van der Putten, Annette A. J, & Vlaskamp, C. (2016). "I love my sister, but sometimes I don't": A qualitative study into the experiences of siblings of a child with profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability*, *41*(4), 279-288. https://doi.org/10.3109/13668250.2016.1224333	Photo elicitation interviews conducted with 18 children who have a sibling with a PIMD indicated both positive & negative influences. Shared activities with the sibling & private time are important for sibling QOL.
33	Marchal, J., Maurice-Stam, H., van Trotsenburg, A., & Grootenhuis, M. (2016). Mothers and fathers of young Dutch adolescents with down syndrome: health related quality of life and family functioning. *Research in Developmental Disabilities*, *59*, 359-369. https://doi.org/10.1016/j.ridd.2016.09.014	Study used HRQOL & family functioning questionnaires to determine whether mothers & fathers of children with Down syndrome differ from reference parents in HRQOL & family functioning.
34	Markowitz, L. A., Reyes, C., Embacher, R. A., Speer, L. L., Roizen, N., & Frazier, T. W. (2016). Development and psychometric evaluation of a psychosocial quality-of-life questionnaire for individuals with autism and related developmental disorders. *Autism*, *20*(7), 832-844. https://doi.org/10.1177/1362361315611382	212 parents of children with ASD completed the Child & FQOL scale prior to diagnostic evaluation. Results found that caregivers of children with ASD reported reduced FQOL prior to diagnosis compared to caregivers of children with other DDs.
35	Mas, J. M., Baqués, N., Balcells-Balcells, A., Dalmau, M., Giné, C., Gràcia, M., & Vilaseca, R. (2016). Family quality of life for families in early intervention in Spain. *Journal of Early Intervention*, *38*(1), 59-74. https://doi.org/10.1177/1053815116636885	Study administered the FQOL Scale to 281 families with children attending an early intervention center. Results found that perceived FQOL varied by income, family type, & severity of disability.
36	McKenzie, J., & McConkey, R. (2016). Caring for adults with intellectual disability: The perspectives of family carers in South Africa. *Journal of Applied Research in Intellectual Disabilities*, *29*(6), 531-541. https://doi.org/10.1111/jar.12209	Focus group discussions with 37 family caregivers indicated that they had a strong commitment to care despite caregiving burden. Many reported "feeling let-down" by community services that are meant to assist them.
37	Nelson Goff, B. S., Monk, J. K., Malone, J., Staats, N., Tanner, A., & Springer, N. P. (2016). Comparing parents of children with Down Syndrome at different life span stages. *Journal of Marriage and Family*, *78*(4), 1131-1148. https://doi.org/10.1111/jomf.12312	Survey study examining experiences of 445 parents of children with Down syndrome. Parents reported higher coping strategy scores during the middle childhood & adolescent years than early childhood or later years.

38	O’Dea, Á., & Connell, A. (2016). Performance difficulties, activity limitations and participation restrictions of adolescents with developmental coordination disorder (DCD). *British Journal of Occupational Therapy*, *79*(9), 540-549. https://doi.org/10.1177/0308022616643100	Study examined data from 141 adolescents with dyspraxia to examine their performance difficulties, activity limitations, participation restrictions & need for health services. Results indicated that cognitive rather than physical impairments affected participation. Access to occupational therapy & psychology is required.
39	Parpa, E., Katsantonis, N., Tsilika, E., Galanos, A., Sassari, M., & Mystakidou, K. (2016). Psychometric properties of the family quality of life scale in Greek families with intellectual disabilities. *Journal of Developmental and Physical Disabilities*, *28*, 393-405.	This study examined the psychometric properties of the Greek version of Beach Center FQOLS (n =180). Results indicate that this version has satisfactory psychometric properties & has to be used among Greek caregivers of people with ID.
40	Patton, H. A. (2016). *Parent-to-Parent Peer Support and Family Quality of Life* [Doctoral dissertation, University of Washington]. https://digital.lib.washington.edu/researchworks/bitstream/handle/1773/38108/Patton_washington_0250E_16745.pdf?sequence=1	Study expanded Beach Center FQOLS items to include families of adults with disabilities. Although there were no significant findings, results of this study showed a clear interest in parent-to-parent support by families of children with disabilities, & higher levels of FQOL for those who participated in such a model.
41	Pulay, A. J., Bitter, I., Papp, S., Gulácsi, L., Péntek, M., Brodszky, V., Hevér, N. V., Rencz, F., & Baji, P. (2016). Exploring the relationship between quality of life (EQ-5D) and clinical measures in adult attention deficit hyperactivity disorder (ADHD). *Applied Research in Quality of Life*, 12(2), 409–424. https://doi.org/10.1007/s11482-016-9467-6	This cross-sectional study examined the relationship between QOL & clinical measures in 75 adults with ADHD using EQ-5D. Results showed connections between EQ-5D & clinical measures, suggesting the former contributes to better understanding of QOL of adult ADHD.
42	Rayan, A., & Ahmad, M. (2016). Effectiveness of mindfulness-based interventions on quality of life and positive reappraisal coping among parents of children with autism spectrum disorder. *Research in Developmental Disabilities*, *55*, 185-196. https://doi.org/10.1016/j.ridd.2016.04.002	Study examined effectiveness of a MBI program on QOL & positive stress reappraisal. Results found that parents in intervention group showed significant improvements in QOL.
43	Samuel, P. S., Pociask, F. D., DiZazzo-Miller, R., Carrellas, A., & LeRoy, B. W. (2016). Concurrent validity of the international family quality of life survey. *Occupational Therapy in Health Care, 30*(2), 187-201. https://doi.org/10.3109/07380577.2015.1116129	Internal consistency & concurrent validity of the FQOLS-2006 was examined using cross-sectional data collected from 65 family caregivers of children with DDs. Results indicated that validity of the FQOL-2006 domains was supported by correlations between conceptually related domains.
44	Schertz, M., Karni-Visel, Y., Tamir, A., Genizi, J., & Roth, D. (2016). Family quality of life among families with a child who has a severe neurodevelopmental disability: Impact of family and child socio-demographic factors. *Research in Developmental Disabilities, 53-54*, 95-106. https://doi.org/10.1016/j.ridd.2015.11.028	This study administered the FQOL survey to primary caregivers who have a child with a severe neurodevelopmental disability (n = 70). Study then looked at the relation to socio-demographics to find that FQOL is mediated by both child & family factors.
45	Schlebusch, L., Samuels, A. E., Dada, S., Högskolan i Jönköping, Högskolan för lärande och kommunikation, & HLK, C. (2016). South African families raising children with	This study used a self-administered survey from 180 families of children with ASD who received disability-related services and investigated the relationship

	autism spectrum disorders: Relationship between family routines, cognitive appraisal, and family quality of life. *Journal of Intellectual Disability Research*, *60*(5), 412-423. https://doi.org/10.1111/jir.12292	between family routines & the impact of ASD on FQOL. The results show that families who have more regular or predictable family routines are more satisfied with their family's QOL.
46	Sexton, E., O'Donovan, M., Mulryan, N., McCallion, P., & McCarron, M. (2016). Whose quality of life? A comparison of measures of self-determination and emotional wellbeing in research with older adults with and without intellectual disability. *Journal of Intellectual & Developmental Disability, 41*(4), 324-337. https://doi.org/10.3109/13668250.2016.1213377	This study compared how QOL is measured in research with adults with & without an ID. Results found that the same measures of emotional wellbeing were shown in both, but concurrent validity between self-determination & emotional wellbeing measures was weak.
47	Sigstad, H. M. H. (2016). Significance of friendship for quality of life in adolescents with mild intellectual disability: A parental perspective. *Journal of Intellectual and Developmental Disability, 41*(4), 289-298. https://doi.org/10.3109/13668250.2016.1200018	This study used qualitative, semi-structured interviews from 6 mothers to examine, how parents assess the significance of friendship in adolescents with mild IDs. Results found that friendships are incredibly important for their QOL and it required more efforts from the parents than for typically developing offspring.
48	Simões, C., & Santos, S. (2016) Comparing the quality of life of adults with and without intellectual disability. *Journal of Intellectual Disability Research*, *60*, 378–388. https://doi.org/10.1111/jir.12256	This study compared QOL among people with & without ID by collecting data from 1264 individuals using the Personal Outcomes Scale. Results found significantly higher QOL for adults without ID.
49	Simões, C., & Santos, S. (2016). The quality of life perceptions of people with intellectual disability and their proxies. *Journal of Intellectual and Developmental Disability.* https://doi.org/10.3109/13668250.2016.1197385	This study focused on 69 individuals with ID using a self-report measure and had a report-of-others section completed by interviewing one family member. Results found a sizeable agreement among people with ID & family members.
50	Tait, K., Fung, F., Hu, A., Sweller, N., & Wang, W. (2016). Understanding Hong Kong Chinese families' experiences of an autism/ASD diagnosis. *Journal of Autism and Developmental Disorders*, *46*(4), 1164-1183. https://doi.org/10.1007/s10803-015-2650-z	This study had 75 parents of children with ASD complete the FQOL Scale & participate in semi-structured interviews. Results found that parents' perceptions of their child's disability were influenced by their cultural background & the pre- & post-diagnostic services available.
51	Taub, T., & Werner, S. (2016). What support resources contribute to family quality of life among religious and secular Jewish families of children with developmental disability? *Journal of Intellectual and Developmental Disability, 41*(4), 348-359. https://doi.org/10.3109/13668250.2016.1228859	This study explored FQOL by examining its specific domains by having 170 Jewish families of children with DD complete a self-administered questionnaire. Results found that religious families reported a higher FQOL, but there were no differences found on familial, social, & service supports.
52	Van Heumen, L., & Schippers, A. (2016). Quality of life for young adults with intellectual disability following individualized support: Individual and family responses. *Journal of Intellectual and Developmental Disability, 1-12*. https://doi.org/10.3109/13668250.2016.1213797	Semi structured interviews with adults with ID to evaluate impact of an individualized support found that most participants evaluated the project as positive in relation to QOL.

53	Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A Systematic Review. *Research in Autism Spectrum Disorders, 23*, 36-49. https://doi.org/10.1016/j.rasd.2015.11.008	Study examined studies measuring QOL of parents of children with ASD. Results found lower QOL among parents of children with ASD compared to parents of typically developing children. Contributing factors included child behavioral difficulties, unemployment, & lack of social support.
54	Wakimizu, R., & Fujioka, H. (2016). Analysis of the issues and needs of parents of children with developmental disabilities in Japan using focus group interviews. *Journal of Nursing Research, 24*(1), 68-78. https://doi.org/10.1097/jnr.0000000000000093	Study examined issues & needs of the parents of children with DD by conducting semi structured interviews with 55 parents. Results found that key concerns include providing relevant information support, providing counseling for family, & providing resources to the children with DDs.
55	Wakimizu, R., Yamaguchi, K., & Fujioka, H. (2016). Family empowerment and quality of life of parents raising children with developmental disabilities in 78 Japanese families. *International Journal of Nursing Sciences, 4*(1), 38-45. https://doi.org/10.1016/j.ijnss.2016.12.004	Survey of 93 parents with children with DDs in capital region of Japan indicated that family empowerment & QOL of these parents were affected by various subscales of family function. Effective interventions for improving FQOL should be researched in the future.
56	Zuna, N., Gràcia, M., Haring, S. H., & Aguilar, J. M. (2016). Parental perceptions and satisfaction with family services in families of children with autism spectrum disorder and other developmental disabilities. *Journal of Intellectual and Developmental Disability, 41*(3), 233-242. https://doi.org/10.3109/13668250.2016.1179272	Study used FQOL & Services Inventory to understand parental satisfaction with services in 100 families of children with IDD. Results indicate that initial assessments should match services to family needs with follow-up to ensure services improved FQOL.

	2017	**Summary of Work**
1	Boehm, T. L. (2017). *Predictors of family quality of life among parents of children and adults with intellectual* disability. [Doctoral dissertation, Vanderbilt Univerisity]. https://ir.vanderbilt.edu/bitstream/handle/1803/11166/Boehm.pdf?sequence=1&isAllowed=y	This study examined the QOL for families with a member with ID. Parents reported overall satisfaction with their FQOL, connecting FQOL to the significant role of parent relationships with family, friends, & professionals. Parents' religiousness/spirituality was a significant predictor of FQOL.
2	Boehm, T. L., Carter, E. W., Taylor, J. L. (2017) Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities 120.5*(2015), 395, 411, 476, 478. https://doi.org/10.1352/1944-7558-120.5.395	FQOL among 425 parents with transition-age youth & young adults with IDD &/or ASD was examined to better understand FQOL & the factors that may shape it. Results found that overall FQOL ratings were higher except in the emotional wellbeing domain reported by the families and strong association between religious faith & FQOL.
3	Burk, B. N., & Sharaievska, I. (2017). Health and recreation perceptions of adults with developmental disabilities. *Therapeutic Recreation Journal*, *51*(3), 179. https://go.gale.com/ps/i.do?id=GALE%7CA51	This study explored 16 adults with DDs attitudes toward healthy eating & active recreation, their intentions & interests for active recreation & barriers to active recreation & healthy eating with an interview with results recommending more education about a healthy lifestyle is needed. The participants reported lack of control in eating habits because of their social circle influence and dependency on caregivers.
4	Burke, M., Chan, N., & Neece, C. (2017). Parent perspectives of applying mindfulness-based stress reduction strategies to special education. *Intellectual and Developmental Disabilities*, *55*(3), 167-180. https://doi.org/10.1352/1934-9556-55.3.167	Interviews were conducted on 26 parents of children with IDD to investigate whether mindfulness may reduce school-related stress by completing a mindfulness-based stress reduction intervention. While most parents reported it as stressful, the parents who reported less stress had strong family school partnership.
5	Cheak-Zamora, N. C., & Thullen, M. (2017). Disparities in quality and access to care for children with developmental disabilities and multiple health conditions. *Maternal and Child Health Journal*, *21*(1), 36-44. https://doi.org/10.1007/s10995-016-2091-0	Disparities in meeting quality & accessibility indicators for children with different condition types were examined using a cross-sectional study. Caregivers reported on (N = 40,242) children using the National Survey of Children with Special Health Care Needs. Results indicated that children with DD & multiple conditions do experience disparities in healthcare.
6	Chiu, C. Y., Seo, H., Turnbull, A. P., & Summers, J. A. (2017). Confirmatory factor analysis of a family quality of life scale for Taiwanese families of children with intellectual disability/developmental delay. *Intellectual and Developmental Disabilities, 55*(2), 57-71. https://doi.org/10.1352/1934-9556-55.2.57	The reliability & validity of the revised Beach Center Family QOL Scale was examined in 400 families of children & youth with ID & developmental delay. Results suggested FQOL Scale-21 can be useful for intervention evaluation, policy making, & service delivery.
7	Chiu, S., Chen, P., Chou, Y., & Chien, L. (2017). The mandarin Chinese version of the Beach Centre Family Quality of Life Scale: Development and psychometric properties in Taiwanese families of children with developmental delay. *Journal of Intellectual Disability*	This study translated the Beach Centre FQOL Scale into Mandarin Chinese to examine the psychometric properties of the scale in families of children with DD using translators and 360 caregivers were used to

	Research, *61*(4), 373-384. https://doi.org/10.1111/jir.12356	validate the scale. Results show the scale has excellent internal consistency reliability.
8	Coghill, D. R., Banaschewski, T., Soutullo, C., Cottingham, M. G., & Zuddas, A. (2017). Systematic review of quality of life and functional outcomes in randomized placebo-controlled studies of medications for attention-deficit/hyperactivity disorder. *European Child & Adolescent Psychiatry*, 26(11), 1283–1307. https://doi.org/10.1007/s00787-017-0986-y	This study explores qualitative data to measure effectiveness of pharmacotherapy on function impairment & HRQOL in adolescents with ADHD using PubMed searching & screening strategies. 291 records were screened. Results indicated defects in HRQOL of adolescents.
9	Collins, P., Pringle, B., Alexander, C., Darmstadt, G., Heymann, J., Huebner, G., Zindel, M. (2017). Global services and support for children with developmental delays and disabilities: Bridging research and policy gaps. *PLOS Medicine*, *14*(9), e1002393. https://doi.org/10.1371/journal.pmed.1002393	Children with developmental delays & behavioral, cognitive, mental & neurological disabilities need better access to health care, early childhood care, education, & developmental services. The study found 5 areas needing intervention: identifying children with delays and disabilities, ensuring access to early childhood school programs for children, training and support of parents/caregivers to strengthen their ability to care for their children, supporting their ability to work, and ensuring that the mental health needs of caregivers are met.
10	Correia, R. A., Seabra-Santos, M. J., Pinto, P. C., & Brown, I. (2017). Giving voice to persons with intellectual disabilities about family quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, *14*(1), 59-67. https://doi.org/10.1111/jppi.12226	This study gave a voice to persons with IDs & to explore their perspectives about their FQOL using 4 focus groups of (n = 17) men & women with ID. Results found that family relationships was the most important dimension for FQOL.
11	Dalmau-Montala, M., Balcells-Balcells, A., Giné, C. G., Pérez, M. C., Masjoan, O. C., Cuscó, Y. S., & Cruz, V. F. (2017). How to implement the family-centered model in early intervention. *Anales De Psicología, 33*(3), 641. https://doi.org/10.6018/analesps.33.3.263611	The authors provide methodology for the implementation of the family-centered model in early childhood intervention centers in Spain using quantitative & qualitative analyses of research data. The model aims to empower the familiies to become more autonomous and les dependent on the professionals.
12	Davis, E., Reddihough, D., Murphy, N., Epstein, A., Reid, S. M., Whitehouse, A., Downs, J. (2017). Exploring quality of life of children with cerebral palsy and intellectual disability: What are the important domains of life? *Child: Care, Health and Development*, *43*(6), 854-860. https://doi.org/10.1111/cch.12501.	Important domains of QOL for children with CP & ID identified in this study by giving structured interviews to 18 parents with children of CP/ID were physical health, body comfort, behaviour and emotion, communication, predictability and routine, movement and physical activity, nature and outdoors, variety of activity, independence and autonomy, social connectedness, and access to services.
13	Hsiao, Y., Higgins, K., Pierce, T., Whitby, P., & Tandy, R. (2017). Parental stress, family quality of life, and family-teacher partnerships: Families of children with autism spectrum disorder. *Research in Developmental Disabilities, 70*, 152-162. https://doi.org/10.1016/j.ridd.2017.08.013	The interrelations among parental stress, FQOL & family-teacher partnerships among (N = 236) parents of children with ASD was examined by completing questionnaires of 3 different scales. Results found perceived parental stress had a direct effect on parental satisfaction concerning FQOL.

14	Ignjatovic, T., Milanovic, M., & Zegarac, N. (2017). How services for children with disabilities in Serbia affect the quality of life of their families. *Research in Developmental Disabilities, 68,* 1-8. https://doi.org/10.1016/j.ridd.2017.06.009	The effect of newly introduced services on the family QOL of children with disabilities was discussed using a pretest/posttest method on 153 families of children with disabilities. Results found the services improved FQOL, family & parenting interaction.
15	Jones, S., Bremer, E., & Lloyd, M. (2017). Autism spectrum disorder: Family quality of life while waiting for intervention services. *Quality of Life Research, 26*(2), 331-342. https://doi.org/10.1007/s11136-016-1382-7	How families with a child with ASD view their overall FQOL & what aspects of everyday life have the greatest influence on the FQOL was explored in 454 families through surveys. Results found that the influential factor for FQOL was whether the child had a major health concern & if the family's needs were met with service.
16	Krajnc, M. S., & Seršen, K. K. (2017). Quality of life for families of children with intellectual disabilities/Druzine z otroki z motnjami v dusevnem razvoju in kakovost zivljenja. *Revija Za Elementarno Izobraževanje*, *10*(1), 5-17. https://journals.um.si/index.php/education/article/view/328	The study describes the FQOL of 44 families of children with IDD in Slovenia using the FQOLS-2006. The *family relationships* domain had the highest average rating while the domains of *informal & formal support* were lowest ranked. Families require support programs from qualified professional teams as well as societal & political attention.
17	McAuliffe, T., Cordier, R., Vaz, S., Thomas, Y., & Falkmer, T. (2017). Quality of life, coping styles, stress levels, and time use in mothers of children with autism spectrum disorders: Comparing single versus coupled households. *Journal of Autism and Developmental Disorders,* 1-15. https://doi.org/10.1007/s10803-017-3240-z	The influence of differences in household status on parental stress, coping, time use & QOL in mothers of children with ASD was studied in mothers (43 single & 164 coupled). Results found that there were slight differences in stress levels between the mothers by family structure of the household.
18	McKenzie, K., Ouellette-Kuntz, H., Blinkhorn, A., & Démoré, A. (2017). Out of school and into distress: Families of young adults with intellectual and developmental disabilities in transition. *Journal of Applied Research in Intellectual Disabilities*, *30*(4), 774-781. https://doi.org/10.1111/jar.12264	The transition period out of the educational system for parents of children with IDD was examined using a before & after design of the Brief Family Distress Scale & Family Support Scale. Results found that parents reported higher levels of distress after their child transitioned out of school.
19	Niemiec, R., Shogren, K., & Wehmeyer, M. (2017). Character strengths and intellectual and developmental disability: A strengths-based approach from positive psychology. *Education and Training in Autism and Developmental Disabilities*, *52*(1), 13-25. https://eric.ed.gov/?id=EJ1129568	An overview of the growing science of character strengths in people with IDD was seen in this paper. As well as why and how character strengths are relevant to people with IDD. A strengths-based perspective in the disability field was examined.
20	Rivard, M., Mercier, C., Mestari, Z., Terroux, A., Mello, C., & Bégin, J. (2017). Psychometric properties of the Beach Center Family Quality of Life in French-speaking families with a preschool-aged child diagnosed with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities, 122*(5), 439-452. https://pubmed.ncbi.nlm.nih.gov/28846039/	An assessment of the psychometric properties of a French translation of The Beach Center FQOLS using data gathered from 452 parents of children newly diagnosed with ASD. The results found that scales of Satisfaction & Importance showed good internal consistency.
21	Samuel, P. S., Tarraf, W., & Marsack, C. (2017). Family Quality of Life Survey (FQOLS-2006): Evaluation of internal consistency, construct, and criterion validity for	The psychometric properties of the FQOLS-2006 was tested among 193 urban family caregivers from socioeconomically disadvantaged backgrounds. Results

	socioeconomically disadvantaged families. *Physical and Occupational Therapy In Pediatrics*, 1-18. https://doi.org/10.1080/01942638.2017.1311393	indicate that the FQOL-2006 had a moderate degree of validity in this population.
22	Schmidt, J., Schmidt, M., & Brown, I. (2017). Quality of life among families of children with intellectual disabilities: A Slovene study. *Journal of Policy and Practice in Intellectual Disabilities*, *14*(1), 87-102. https://doi.org/10.1111/jppi.12188	QOL data for 25 families who have children with IDD & 19 families in which children had ID with ASD was examined using the FQOLS-2006. Results found that families that have a member with IDD had better QOL than for those that have a member with ASD.
23	Shivers, C., & Dykens, E. (2017). Adolescent siblings of individuals with and without intellectual and developmental disabilities: Self-reported empathy and feelings about their brothers and sisters. *American Journal on Intellectual and Developmental Disabilities*, *122*(1), 62-77. https://doi.org/10.1352/1944-7558-122.1.62	Survey research on 97 adolescent siblings of individuals with & without IDD indicated that siblings of individuals with IDD have higher anxiety towards the siblings with IDD than those without.
24	Spindler, U. P., Hotopp, L. C., Bach, V. A., Hornemann, F., Syrbe, S., Andreas, A., Bertsche, A. (2017). Seizure disorders and developmental disorders: Impact on life of affected families— A structured interview. *European Journal of Pediatrics*, *176*(8), 1121-1129. https://doi.org/10.1007/s00431-017-2958-0	Investigators interviewed 307 parents of children with seizure disorders and/or developmental disorder, on the constraints of daily living and reported that more constraints present in combination disorder especially employment and parental relationships. 1 in 2 children faced discrimination from family and teachers.
25	Tait, K., & Hussain, R. (2017). Using quality of family life factors to explore parents' experience of educational provision for children with developmental disabilities in rural Australia. *International Journal of Disability, Development and Education*, *64*(3), 328-344. https://doi.org/10.1080/1034912X.2016.1223280	Beach center FQOLS used to examine 51 parents' experience of education service provision. Results showed that successful engagement with the school system is affected by views, assumptions, expertise and prejudices of teaching & care professionals.
26	Totsika, V., Hastings, R. P., & Vagenas, D. (2017; 2016). Informal caregivers of people with an intellectual disability in England: Health, quality of life and impact of caring. *Health & Social Care in the Community*, *25*(3), 951-961. https://doi.org/10.1111/hsc.12393	Health & QOL impact of caring for 260 informal caregivers of people with an ID was examined. Results show that there was a higher risk of negative impact on caregivers' personal life & financial situations.
27	Turnbull, R., & Stowe, M. (2017). A model for analyzing disability policy. *Intellectual and Developmental Disabilities*, *55*(4), 223-233. https://doi.org/10.1352/1934-9556-55.4.223	A 12-step model that can be used for policy analysis was discussed. It also addressed application issues & different conceptualizations of persons with IDD.
28	Vilaseca, R., Gràcia, M., Beltran, F. S., Dalmau, M., Alomar, E., Adam-Alcocer, A. L., & Simó-Pinatella, D. (2017). Needs and supports of people with intellectual disability and their families in Catalonia. *Journal of Applied Research in Intellectual Disabilities*, *30*(1), 33-46. https://doi.org/10.1111/jar.12215	An examination of FQOL for 2160 families with an individual with IDD in Catalonia was assessed, using the Needs & Supports for People with IID & their Families questionnaire. Results found the mean FQOL was high for this sample.
29	Zaidman-Zait, A., Curle, D., Jamieson, J. R., Chia, R., & Kozak, F. K. (2017). Health-related quality of life among young children with cochlear implants and developmental disabilities. *Ear and Hearing, 38*(4), 399-408. https://doi.org/10.1097/aud.0000000000000410	Differences in HRQOL between deaf children with cochlear implant with & without DDs were examined in 92 parents who completed the KINDL questionnaire. Results found children in the CI-DD group had a lower HRQOL.

	2018	**Summary of Work**
1	Alhazmi, A., Petersen, R., & Donald, K. A. (2018). Quality of life among parents of South African children with autism spectrum disorder. *Acta Neuropsychiatrica*, *30*(4), 226–231. https://doi.org/10.1017/neu.2018.5	This article compares the QOL of parents caring for children with ASD with parents of typically developing (TD) children from the same community and the scores of four QOL domains such as Physical, psychological, social and environmental health were low in parents caring for children with ASD.
2	Anto, S. T. (2018). Family quality of life (FQOL) of parents of children with intellectual and developmental disabilities enrolled in private mental retardation school, at Thrissur. *International Journal of Nursing Education and Research*, *6*(2), 138. https://doi.org/10.5958/2454-2660.2018.00033.9	This study evaluated the FQOL of 30 parents of children with IDDs by using a non-experimental descriptive study design with a non-probability, convenient sampling technique, comparing FQOL with the sociodemographic variables of parents.
3	Arias, V. B., Gómez, L. E., Morán, L., A, et al. (2018). Does quality of life differ for children with autism spectrum disorder and intellectual disability compared to children without autism? *Journal of Autism and Developmental Disorders, 48*(1), 123-136. A*utism*, *48*(1), 123-136. https://doi.org/10.1007/s10803-017-3289-8	This study tested if 1060 children with ID & ASD show lower QOL in comparison to those with only ID. Results indicated those with ASD showed lower scores in several QOL domains. When the effect of other variables was controlled, lower scores were seen for interpersonal relationships, social inclusion, & physical wellbeing. Slightly higher scores found for material wellbeing.
4	Blaskowitz, M. G., Famularo, E., Lonergan, M., McGrady, E., Layer, L., Randall, L., & Zelenko, M. (2018). Closing the gap: Identifying quality-of-life disparities for young adults with intellectual and developmental disabilities in transition. *The American Journal of Occupational Therapy*, *72*. https://doi.org/10.5014/ajot.2018.72s1-po1020	This poster presented an exploratory observational study using data from 30 individuals with IDDs to identify their QOL disparities. Results indicated that there are QOL differences between young adults in transition with IDD & those without.
5	Boelsma, F., Schippers, A., Dane, M., & Abma, T. A. (2018). "Special" families and their "normal" daily lives: Family quality of life and the social environment. *International Journal of Child, Youth and Family Studies*, *9*(4), 107–124. https://doi.org/10.18357/ijcyfs94201818643	This article focused on the social & societal factors that influence FQOL. In this multiple case study 55 family members of 25 families with ID/DD children were interviewed using FQOLSurvey-2006 and the Beach Center FQOL Scale. The study reports that lack of acceptance and understanding can be impeding factors for the FQOL of the participating families.
6	Büğüşan, S., Kahraman, A., Elbasan, B., & Mutlu, A. (2018). Do adolescents with cerebral palsy agree with their caregivers on their participation and quality of life? *Disability and Health Journal*, *11*(2), 287–292. https://doi.org/10.1016/j.dhjo.2017.10.009	This study focused on 26 children with CP, their participation levels and QoL using the Pediatric Outcomes Data Collection Instrument (PODCI) to assess differences in participant and caregiver's perspective. Caregiver and child answers differed in subjective assessments domain (e.g., happiness & pain). Results suggest that using proxy assessments of QOL are not reliable.
7	Caples, M., Martin, A., Dalton, C., Marsh, L., Savage, E., Knafl, G., & Riper, M. V. (2018). Adaptation and resilience in families of individuals with Down syndrome living in Ireland. *British*	The study analyzed the survey completed by 95 parents of children with Down syndrome. The measures used were Family Index of Regenerativity

	Journal of Learning Disabilities. https://doi.org/10.1111/bld.12231	and Adaptation General (FIRA-G), Family Management Measure (FaMM), Family Member Well-Being Index (FMWB), Brief Family Assessment Measure-General (BFAM-G). Affirmative communication & hardiness have a positive effect and family strain had negative impact on the family functioning.
8	Cardell, B., & Benson, J. (2018). Development of a cognitively accessible self-report measure of health-related quality of life in people with intellectual and developmental disabilities. *The American Journal of Occupational Therapy*, *72.* https://doi.org/10.5014/ajot.2018.72s1-po1004	This poster describes the development of a valid & reliable self-report measure on HRQOL for people with IDD, using community-based participatory research.
9	Derguy, C., Roux, S., Portex, M., & M'bailara, K. (2018). An ecological exploration of individual, family, and environmental contributions to parental quality of life in autism. *Psychiatry Research*, *268*, 87–93. https://doi.org/10.1016/j.psychres.2018.07.006	115 parents of children with ASD were participants in a study. Focus investigated predictors of parental QOL among child-related, parent-related & environmental factors. This study highlights that family environment and psychoeducational interventions for child are decisive for parental quality of life and emphasis the importance of considering the relationship within the couple and within the parent-grandparents dyad.
10	Friedman, C. (2018). Direct support professionals and quality of life of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *56*(4), 234–250. https://doi.org/10.1352/1934-9556-56.5.234	The relationship between direct support professionals and 1,300 people with IDD QOL was examined, using personal outcome measures & interviews. Results found that DSP is central to QOL in this population.
11	Gardiner, E., & Iarocci, G. (2018). Examining family quality of life within the context of a participant-directed ASD funding program in British Columbia, Canada. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(2), 110–123. https://doi.org/10.1111/jppi.12237	This study examined 118 caregivers of children with ASD & their perceptions of service access in terms of FQOL and reported that the average satisfaction rating was low. The caregivers also expressed the system was complicated, inaccessible and inflexible.
12	Hsai, Y. J. (2018). Autism spectrum disorders: Family demographics, parental stress, and family quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(1), 70–79. https://doi.org/10.1111/jppi.12232	This article examined the impact of family demographic characteristics & parental stress on the QOL in families of children with ASD by collecting responses from 236 parents of children with ASD. The study was based on the Beach Center FQOL Scale & the Parental Stress Scale. Parental stress and family income were significant predictor of QOL.
13	Jain, A., Sullivan, B. T., Shah, S. A., Samdani, A. F., Yaszay, B., Marks, M. C., & Sponseller, P. D. (2018). Caregiver perceptions and health-related quality-of-life changes in cerebral palsy patients after spinal arthrodesis. *Spine*, *43*(15), 1052–1056. https://doi.org/10.1097/brs.0000000000002508	This study examined caregivers' perceptions regarding changes in the HRQOL of patients with CP after spinal arthrodesis in terms of three criteria: a qualitative assessment of changes in global QOL, comfort, & health; relative valuation of spine surgery versus other common interventions in CP patients; & quantitative changes in HRQL scores.
14	Keawutan, P., Bell, K. L., Oftedal, S., Davies, P. S. W., Ware, R. S., & Boyd, R. N. (2018). Quality of life and habitual physical activity in children with cerebral palsy aged 5 years: A cross-	The study assessed 58 children using 66-item Gross Motor Function Measure and analyzed the parent proxy Cerebral Palsy Quality of Life questionnaire for Children (CP QOL-Child) The Parent-reported QOL for

	sectional study. *Research in Developmental Disabilities*, *74*, 139–145. https://doi.org/10.1016/j.ridd.2018.01.008	ambulant children with CP aged 5 years was significantly better than that of non-ambulant children with CP.
15	Kyrkou, M. R. (2018). Health-related family quality of life when a child or young person has a disability. *International Journal of Child, Youth and Family Studies*, *9*(4), 49–74. https://doi.org/10.18357/ijcyfs94201818640	This article was built on information from earlier publications. The study illustrated relevant issues & the innovative methods parents, caregivers, & professionals have devised to enhance the HRQOL/FQOL for children & young people with disabilities.
16	Lee, C. Eun, & Burke, M. M. (2018). Caregiving roles of siblings of adults with intellectual and developmental disabilities: A systematic review. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(3), 237–246. https://doi.org/10.1111/jppi.12246	Literature review of 29 studies on adult sibling caregivers for a person with IDD indicated that sibling caregiving has benefits & challenges. Results indicate that there is no consistent definition of sibling caregiving and mixed literature on the correlates of sibling caregiving. It is necessary to conduct research to understand sibling caregiving for individuals with IDD.
17	Lei, X. (2018). Study on relationship between family cohesion and adaptability, and quality of life of caregivers of children with ASD. *Social Welfare: Interdisciplinary Approach*, *8*(1), 132–143. https://doi.org/10.21277/sw.v1i8.340	This study with 163 caregivers of children with ASD in China evaluated family cohesion, adaptability, & QOL (Beach FQOL Scale). Caregivers of children with ASD had higher family cohesion, lower adaptability, and medium FQOL. Family cohesion and adaptability were significantly correlated with FQOL and had a positive impact on FQOL.
18	Lima-Rodríguez, J. S., Baena-Ariza, M. T., Domínguez-Sánchez, I., & Lima-Serrano, M. (2018). Intellectual disability in children and teenagers: Influence on family and family health. Systematic review. *Enfermería Clínica (English Edition)*, *28*(2), 89–102. https://doi.org/10.1016/j.enfcle.2017.10.007	This literature review examined the influence of a child or adolescent with IDs on the family unit using publications from 2013-2018. Mothers assume greater responsibility, and their wellbeing is lower than that of fathers. Having the support of the husband improves their QOL.
19	Maestro-Gonzalez, A., Bilbao-Leon, M. C., Zuazua-Rico, D., Fernandez-Carreira, J. M., Baldonedo-Cernuda, R. F., & Mosteiro-Diaz, M. P. (2018). Quality of life as assessed by adults with cerebral palsy. *PLOS One*, *13*(2). https://doi.org/10.1371/journal.pone.0191960	This is a descriptive cross-sectional study of 75 individuals with CP in Spain, & their QOL was measured using the GENCAT QOL Scale. The overall mean score indicator of participants' QOL was 103.29, which corresponds to the 56.6th percentile on the GENCAT scale. Significant differences in the factors "personal development" and "self-determination," and those with a university education obtained higher scores than their less-educated counterparts. Having a partner was related to higher QOL, and maintaining sexual relationships increased QOL.
20	Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research*, *11*(8), 1138–1147. https://doi.org/10.1002/aur.1965	A total of (N = 370) adults with ASD from the Adult Autism Spectrum Cohort-UK (ASC-UK) completed the WHOQoL-BREF, the Social Responsiveness Scale (SRS, ASD symptom severity), & the ASC-UK registration questionnaire. Results provided information on mental health & their life situation.

21	Ncube, B. L., Perry, A., & Weiss, J. A. (2018). The quality of life of children with severe developmental disabilities [SDD]. *Journal of Intellectual Disability Research*, *62*(3), 237–244. https://doi.org/10.1111/jir.12460	An online survey study of 246 parents of children (4-18 years) with SDD & 210 parents of typically developing (TD) children regarding child QOL based on child's happiness, achievement of potential & friendship quality. Children with SDD had lower QoL than TD children. In children with SDD, higher QoL was related to younger age, higher adaptive skills, lower maladaptive behaviour, lower parent psychological distress and higher satisfaction with the child's education.
22	Omura, J., Fuentes, M., & Bjornson, K. (2018). Participation in daily life: Influence on quality of life in ambulatory children with cerebral palsy. *PM&R*, *10*(11), 1185–1191. https://doi.org/10.1016/j.pmrj.2018.05.010	Secondary analysis, cross-sectional cohort study e to examine levels of participation to QOL in ambulatory children with CP. Participation was negatively associated with increasing Gross Motor Function Classification System but not age. Level of participation was associated with psychosocial QOL and total QOL but not with physical QOL. There was a positive relationship between physical activity performance, walking performance, and communication level with physical QOL. Increasing age & decreased frequency of participation were negatively associated with all QOL domains.
23	Ozgur, B. G., Aksu, H., & Eser, E. (2018). Factors affecting quality of life of caregivers of children diagnosed with autism spectrum disorder. *Indian Journal of Psychiatry*, *60*(3), 278. https://doi.org/10.4103/psychiatry.indianjpsychiatry_300_17	QoL and factors affecting the QoL of 162 caregivers of children with ASD investigated using the QOL in Autism Questionnaire-Parent Version (QoLA-P), ASD behavior checklist & clinical global impression scale. QoL of caregiver and family was negatively affected related to the characteristics of the disorder. Lower well-being, more depressive symptoms, and higher anxiety reported by mothers of children with high-functioning ASD when compared to mothers of normally developing children.
24	Ozkan, Y. (2018). Child’s quality of life and mother’s burden in spastic cerebral palsy: A topographical classification perspective. *Journal of International Medical Research*, *46*(8), 3131–3137. https://doi.org/10.1177/0300060518772758	The Pediatric QOL Inventory & Zarit Burden Interview used to evaluate 120 children with spastic CP (diplegia, hemiplegia, & quadriplegia). Children’s QoL scores were lower in the quadriplegia group than in the hemiplegia and diplegia groups (except for emotional functioning). Maternal burden was lower in quadriplegia group than others, and lower in diplegia compared to hemiplegia group. Increased children’s QoL associated with decreased maternal burden.
25	Polack, S., Adams, M., O'banion, D., Baltussen, M., Asante, S., Kerac, M., Gladstone, M., Zuurmond, M. (2018). Children with cerebral palsy in Ghana: Malnutrition, feeding challenges, and caregiver quality of life. *Developmental Medicine and Child Neurology*, *60*(9), 914–921. https://doi.org/10.1111/dmcn.13797	76 caregivers of children with CP in Ghana evaluated using the Pediatric QOL Inventory Family Impact Module to assess how malnutrition and feeding difficulties affect caregiver QOL. 65% of children under 5 years were underweight, 54% stunted, and 58% wasted. Feeding challenges were common and

		significantly associated with the child being underweight and poorer caregiver QoL.
26	Power, R., King, C., Muhit, M., Heanoy, E., Galea, C., Jones, C., Badawi, N. and Khandaker, G. (2018). Health-related quality of life of children and adolescents with cerebral palsy in low- and middle-income countries: A systematic review. *Developmental Medicine and Child Neurology*, *60*(5), 469–479. https://doi.org/10.1111/dmcn.13681	This literature review systematically reviewed 6 key bibliographic databases, two reviewers independently screened results, & peer-reviewed original articles on HRQOL of children & adolescents with CP from low- & middle-income countries (LMICs), Goal was to identify trends in HRQOL & areas for future research.
27	Reid, S.M., Meehan, E.M., Arnup, S.J. and Reddihough, D.S. (2018). Intellectual disability in cerebral palsy: A population-based retrospective study. *Developmental Medicine and Child Neurology*, *60*(7), 687–694. https://doi.org/10.1111/dmcn.13773	A population-based observational study design with survival analysis in a 30-year birth cohort (n = 3248) was used to describe the epidemiology of ID in CP in terms of clinical & neuroimaging associations. Study reported the impact of ID on utilization of health services & length of survival.
28	Santoro, A. F., Shear, S. M., & Haber, A. (2018). Childhood adversity, health and quality of life in adults with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, *62*(10), 854–863. https://doi.org/10.1111/jir.12540	The relationship among adversity, physical health & QOL in 127 adults with IDD was examined using the participants medical records. Results found that individuals with IDD experience more adversity than the general population.
29	Wang, Y., Xiao, L., Chen, R., Chen, C., Xun, G., Lu, X., Shen, Y., Wu, R., Xia, K., Zhao, J., Ou, J. (2018). Social impairment of children with autism spectrum disorder affects parental quality of life in different ways. *Psychiatry Research*, *266*, 168–174. https://doi.org/10.1016/j.psychres.2018.05.057	The study included (n = 406) families of children with ASD & (n = 513) families with typically developing (TD) children. Results evaluated the life quality of Chinese parents of preschool children with ASD & their association with child social impairment & childcare burden.
30	White, K., Flanagan, T. D., Nadig, A. (2018). Examining the relationship between self-determination and quality of life in young adults with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, *30*(6), 735–754. https://doi.org/10.1007/s10882-018-9616-y	This study examined the relationship between two complementary measures of SD, namely the Arc's Self-Determination Scale and the AIR Self-Determination Scale, & QOL in 30 young adults with ASD but without ID. This was done through a completed self-report questionnaire of SD & QOL and the report shows that SD is significant positive predictor of QOL and intellectual functioning was not associated with QOL.

	2019	**Summary of Work**
1	Alonso-Sardón, M., Iglesias-de-Sena, H., Fernández-Martín, L. C., Mirón-Canelo, J. A. (2019). Do health and social support and personal autonomy have an influence on the health-related quality of life of individuals with intellectual disability? *BMC Health Services Research*, *19*(1), 1-10. https://doi.org/10.1186/s12913-018-3856-5	A cross-sectional study with a multicenter sample was investigated including 162 institutionalized individuals with ID through structured questionnaires with sociodemographic variables & three scales. The scales include the Functional Independence Measure (FIM) scale, Duke-UNC Functional Social Support Questionnaire, & SF-36 Health Survey. The study reports that the individual in institutional or non-institutional settings with higher degree of personal autonomy receiving family and social support has higher General Health, Well-being and HRQoL than subjects who are more dependent and have less support.
2	Balcells-Balcells, A., Giné, C., Guàrdia-Olmos, J., Summers, J. A., Mas, J. M. (2019). Impact of supports and partnership on family quality of life. *Research in Developmental Disabilities*, *85*, 50-60. https://doi.org/10.1016/j.ridd.2018.10.006	This article included 202 families of children with IDD. They used the structural equation model to analyze the influence that the adequacy of the supports & partnerships exerted on FQOL.
3	Barros, ALO, de Gutierrez, GM, Barros, AO, Santos, MTBR. (2019). Quality of life and burden of caregivers of children and adolescents with disabilities. *Special Care in Dentistry*, *39*(4), 380-388. http://doi.org/10.1111/scd.12400	A cross-sectional study was examined with a sample composed of PCCYAs (N = 336) with CP (n = 84), Down Syndrome (n = 84), ASD (n = 84), & without disabilities (control group: CG n = 84). Participants were matched by gender & age. The burden of caregivers was assessed with the Zarit Burden Interview (ZBI); QOL was assessed using WHOQOL-BREF.
4	Bathelt, J., de Haan, M., & Dale, N. J. (2019). Adaptive behaviour and quality of life in school-age children with congenital visual disorders and different levels of visual impairment. *Research in Developmental Disabilities*, *85*, 154- https://doi.org/10.1016/j.ridd.2018.12.003	The study assessed differences in adaptive behavior in children with congenital visual disorders & various levels of visual impairment. The study also assessed their influence on QOL & everyday strengths & difficulties.
5	Bertelli, M. O., Bianco, A., Rossi, A., Mancini, M., La Malfa, G., & Brown, I. (2019). Impact of severe intellectual disability on proxy instrumental assessment of quality of life. *Journal of Intellectual & Developmental Disability, 44*(3), 272-281. https://doi.org/10.3109/13668250.2017.1350835	This study investigated the impact severe ID may have on proxy attribution of QOL in instrumental assessment. Results suggested that prejudicial attitudes towards the QOL of people with severe ID may be absent in proxies or contained within the exercise scope.
6	Boehm, T. L., & Carter, E. W. (2019). Family quality of life and its correlates among parents of children and adults with intellectual disability: AJMR. *American Journal on Intellectual and Developmental Disabilities, 124*(2), 99-115,186,188. https://dx.doi.org/10.1352/1944-7558-124.2.99	This study focused on FQOL among (N = 529) parents with children or adults with ID. Parents reported moderate to high levels of FQOL satisfaction, with some variability across domains. Results highlighted the significance of both informal & formal social relationships, as well as spirituality/religiosity contributing to FQOL.

7	Bohadana, G., Morrissey, S., & Paynter, J. (2019). Self-compassion: A novel predictor of stress and quality of life in parents of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *49*(10), 4039-4052. https://doi.org/10.1007/s10803-019-04121-x	Parents (N = 139) completed an online questionnaire, investigating known predictors & self-compassion. Results indicated higher scores on the positive dimension of self-compassion were associated with better QOL. Higher scores on the negative dimension of self-compassion were associated with greater stress.
8	DaWalt, L. S., Usher, L. V., Greenberg, J. S., & Mailick, M. R. (2019). Friendships and social participation as markers of quality of life of adolescents and adults with Fragile X syndrome and autism. *Autism*, *23*(2), 383-393. https://doi.org/10.1177/1362361317709202	This study examined the friendships, social & recreational activities, & family social networks of individuals with ID from two distinct diagnostic groups: individuals diagnosed with fragile X syndrome (n = 81) compared to those diagnosed with ASD (n = 226).
9	Downs, J., Jacoby, P., Leonard, H., Epstein, A., Murphy, N., Davis, E., & Williams, K. (2019). Psychometric properties of the quality of life inventory- disability (QI-Disability) measure. *Quality of Life Research*, *28*(3), 783-794. https://doi.org/10.1007/s11136-018-2057-3	QI-Disability was administered to 253 primary caregivers of children with ID across four diagnostic groups: Rett syndrome, Down Syndrome, CP, or ASD. The study evaluated the daily challenges beyond those captured in current QOL measures.
10	Eskow, K. G., Chasson, G. S., & Summers, J. A. (2019). The role of choice and control in the impact of autism waiver services on family quality of life and child progress. *Journal of Autism and Developmental Disorders*, *49*(5), 2035- 2048. https://link.springer.com/article/10.1007/s10803-019-03886-5	This study replicated & expanded prior research using propensity score matching of 460 families. Results found that HCBS waivers have a positive impact on FQOL & aspects of child progress. Results revealed having choices in the selection of services, as well as control over day-to-day provision of services, strengthened both the child & family impacts of the Waiver services.
11	Friedman, C. (2019). Quality-of-life outcomes of older adults with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, *44*(4), 237-250. https://doi.org/10.1177/1540796919879227	This study explored QOL outcomes of older adults with severe disabilities by analyzing Personal Outcome Measures® data from 800 people with severe disabilities aged 55 years old & older.
12	Friedman, C., & VanPuymbrouck, L. (2019). The impact of people with disabilities choosing their services on quality of life outcomes. *Disability and Health Journal*, *12*(2), 187-194. https://doi.org/10.1016/j.dhjo.2018.11.011	This study answered two questions: factors predict PWD choosing their services – who was most/least likely to choose their services &, how does choosing their services affect the QOL of PWD through Personal Outcome Measures® interviews from approximately 1100 PWD.
13	Hillebrecht, A. L., Hrasky, V., Anten, C., & Wiegand, A. (2019). Changes in the oral health-related quality of life in adult patients with intellectual disabilities after dental treatment under general anesthesia. *Clinical Oral Investigations*, *23*(10), 3895-3903. https://doi.org/10.1007/s00784-019-02820-4	This study assessed self- & proxy-rated changes in the oral health-related quality of life (OHRQoL) in 52 adult patients with IDs after dental treatment in general anesthesia.
14	Jeoung, B. (2019). Study of the relationships between the health condition, caring in terms of health practice behavior on quality of life of parents of with developmental disabilities. *Journal of Exercise Rehabilitation*, *15*(6), 826. https://doi.org/10.12965/jer.1938736.368	This study examined QOL questionnaire. The health practice behavior questionnaire comprised details of health condition, caring behavior, & diet, & it used a 10-point scale for scoring of 243 parents of children with DDs.

15	Karaivazoglou K, Papadaki E, Iconomou G, Touliatos G, Kotsopoulos S, Assimakopoulos K. (2019). Psychological distress and health-related quality of life in parents of children referred to an outpatient service for children with developmental disorders. *Australasian Psychiatry*, *27*(2), 152-156. https://doi.org/10.1177/1039856218815754	The Hospital Anxiety & Depression Scale & the Short Form 36 Health Survey were used to assess anxiety, depression & QOL in 95 parents of children referred for developmental evaluation, in comparison with 35 parents of healthy children. Parents of children with DD reported increased anxiety, depression, worse social functioning, and mental health. More children in the family were correlated with higher anxiety, while higher child age was associated with more anxiety symptoms, more role limitations due to emotional problems, & worse mental health.
16	Karin C. J. M. de Geus-Neelen, Wietske M. W. J. van Oorsouw, Lex A. H. C. Hendriks & Petri J. C. M. Embregts. (2019). Perceptions of staff and family of the quality of life of people with severe to profound intellectual disability. *Journal of Intellectual and Developmental Disability*, *44*(1), 42-50. https://doi.org/10.3109/13668250.2017.1310813	Since staff and relatives make proxy judgements about QOL for people with severe to profound ID, it is important to know how their perceptions align. 51 staff-family dyads completed the QOL-PMD questionnaire and agreement between proxies assessed statistically. Proxies agreed strongly about applicability of questionnaire items and about the client's QOL, except for items related to internal, subjective experiences (e.g., sexual fulfillment, pain).
17	Kim, S. Y., & Bottema-Beutel, K. (2019). A meta regression analysis of quality of life correlates in adults with ASD. *Research in Autism Spectrum Disorders*, *63*, 23-33. https://doi.org/10.1016/j.rasd.2018.11.004	This study investigated correlations between QOL & several putative correlates, including age, IQ, ASD severity, & social functioning of 1721 participants with ASD. Results found little to no significance for all factors except social functioning.
18	Kim, S. Y. (2019). The experiences of adults with autism spectrum disorder: Self-determination and quality of life. *Research in Autism Spectrum Disorders*, *60*, 1-15. https://doi.org/10.1016/j.rasd.2018.12.002	This study revolved around empirical studies in peer-reviewed journals that described first-hand experiences of adults with ASD within 44 identified studies & 14 general studies. Evidence included of self-determined behaviors in adults with ASD, showing self-determination is correlated to QOL.
19	Lee, M. H., Matthews, A. K., & Park, C. (2019). Determinants of health-related quality of life among mothers of children with cerebral palsy. *Journal of Pediatric Nursing*, *44*, 1-8. https://doi.org/10.1016/j.pedn.2018.10.001	This cross-sectional study focused 180 mothers of children with CP. Study identified the determinants affecting HRQOL among mothers of children with CP. Results found higher HRQOL was related to lower parental stress.
20	Lombardi, M., Vandenbussche, H., Claes, C., Schalock, R.L., De Maeyer, J. and Vandevelde, S. (2019). The concept of quality of life as framework for implementing the UNCRPD. *Journal of Policy and Practice in Intellectual Disabilities*, *16*(3), 180-190. https://doi.org/10.1111/jppi.12279	This study described the perspectives of 153 experts (self-advocates, professionals, family members, academics, & experts in law) from 11 countries to establish consensus on cross-culturally referenced indicators of QOL outcome.

		Experts explored the QOL framework to implement the UNCRPD.
21	Marsack-Topolewski, C. N., & Church, H. L. (2019). Impact of caregiver burden on quality of life for parents of adult children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, *124*(2), 145-156. https://doi.org/10.1352/1944-7558-124.2.145	This study examined the impact of time, developmental, emotional, & financial burdens on the QOL of parents of adult children with ASD in a cross-sectional survey research study. Responses form 320 parents suggests that developmental burden is the strongest predictor of parental QOL.
22	Matteucci M. C., Scalone, L., Tomasetto, C., Cavrini G., Selleri, P. (2019). Health-related quality of life and psychological wellbeing of children with specific learning disorders and their mothers. *Research in Developmental Disabilities*, *87*, 43-53. https://doi.org/10.1016/j.ridd.2019.02.003	This study examines HRQOL & psychological well-being among 30 children with SpLD & their mothers. It was found that children with SpLD reported lower levels of psychosocial health, while mothers had a higher probability of being anxious &/or depressed.
23	McCarron, M., Lombard-Vance, R., Murphy, E., May, P. (2019). Effect of deinstitutionalization on quality of life for adults with intellectual disabilities: A systematic review. *BMJ Open*, *9*(4), e025735. http://dx.doi.org/10.1136/bmjopen-2018-025735	13 studies (8 quantitative, 2 qualitative, 2 mixed methods, one case study) were analyzed. QoL for people with any level of ID who move from institutional setting to community setting increased at up to 1-year postmove (standardised mean difference [SMD] 2.03, five studies, 246 participants) & beyond 1-year postmove (SMD 2.34, three studies, 160 participants), with total QoL change scores higher at 24 months comparative to 12 months, regardless of QoL measure used. Moving to a supportive community was associated with improved QOL compared with the institution.
24	Mello, C., Rivard, M., Terroux, A., Mercier, C. (2019). Quality of life in families of young children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities*, *124*(6), 535-548.https://doi.org/10.1352/1944-7558-124.6.535	The present study investigated FQOL as experienced by 493 mothers & 295 fathers of young children with ASD prior to receiving early intervention services. Results found family characteristics associated with financial & personal resources, age, & number of children were associated with FQOL of mother.
25	Nieuwenhuijse, A. M., Willems, D. L., Van Goudoever, J. B., Echteld M. A., Olsman, E. (2019). Quality of life of persons with profound intellectual multiple disabilities: A narrative literature review of concepts, assessment methods and assessors. *Journal of Intellectual and Developmental Disability*, *44*(3), 261-271. https://doi.org/10.3109/13668250.2017.1388913	21 articles reviewed to understand the challenges in researching QOL of persons who are nonverbal. Results concluded, triangulation appears to be good practice in QOL assessment. Role of proxies in assessing QOL of persons with PIMD needs further investigation.
26	Reid, N., & Moritz, K. M. (2019). Caregiver and family quality of life for children with fetal alcohol spectrum disorder. *Research in Developmental Disabilities*, *94*, 103478. https://doi.org/10.1016/j.ridd.2019.103478	109 caregivers of children with FASD completed a survey that assessed FQOL (*PedsQL Family Impact Module:* 36-item tool), caregiver mental health, & child behavior. Most impacted on the PedsQL module were Family Daily Activities and Worry. Caregiver's country of residence, mental health,

		child gender, and behavioral problems were found to be predictors of caregiver and FQOL.
27	Schepens, H. R., Van Puyenbroeck, J., & Maes, B. (2019). How to improve the quality of life of elderly people with intellectual disability: A systematic literature review of support strategies. *Journal of Applied Research in Intellectual Disabilities*, *32*(3), 483-521. https://doi.org/10.1111/jar.12559	A narrative approach was conducted to identify age-specific support strategies that can improve QOL of people with IDD aged ≥50 years. A systematic search of peer-reviewed publications since 1995 yielded 73 viable articles with 12 themes. Results suggested the need for provision of good housing or activities, support when these provisions change, provision of (mental) health care, dementia care & end-of-life care, life story work, future planning & support for (I)ADLs.
28	Schroder, C. M., Malow, B. A., Maras, A., s, Melmed, R. D., Findling, R. L., Breddy, J., Nir, T., Shahmoon, S., Zisapel, N. (2019). Pediatric prolonged-release melatonin for sleep in children with autism spectrum disorder: Impact on child behavior and caregiver's quality of life. *Journal of Autism and Developmental Disorders*, *49*(8), 3218-3230. https://doi.org/10.1007/s10803-019-04046-5	A randomized, 13-weeks, placebo-controlled double-blind study with 125 children with ASD, Smith-Magennis syndrome, &/or insomnia showed efficacy & safety of easily-swallowed prolonged-release melatonin mini-tablets (PedPRM; 2–5 mg). Results found pills improved QOL of caregivers.
29	Shpigelman, C. (2019). A proposed framework for using the life-coaching process to enhance the quality of life of individuals with intellectual and developmental disabilities: A case study. *Journal of Policy and Practice in Intellectual Disabilities, 16*(3), 150-159. https://doi.org/10.1111/jppi.12276	A case study of two Caucasians with IDD to show feasibility of a conceptual framework for practicing life-coaching. Results indicated potential effectiveness in leveraging the capability set of persons with IDD in various life domains that must be tailored to meet the individual's needs & competencies.
30	Xu, W., Yao, J., & Liu, W. (2019). Intervention effect of sensory integration training on the behaviors and quality of life of children with autism. *Psychiatria Danubina*, *31*(3), 340-346. https://doi.org/10.24869/psyd.2019.340	This study examined the joint effect of SIT & exercise intervention on the behaviors & QOL of 108 children with ASD. Results proved successful with some limitations.

	2020	**Summary of Work**
1	Adams, D., Clark, M., & Simpson, K. (2020). The relationship between child anxiety and the quality of life of children, and parents of children, on the autism spectrum. *Journal of Autism and Developmental Disorders, 50*(5), 1756-1769. https://doi.org/10.1007/s10803-019-03932-2	In this study, 64 parents of children on the spectrum completed questionnaires on their child's ASD characteristics, anxiety symptomatology, & both child (PedsQL) & parent QoL (WHOQoL-BREF). Children with elevated anxiety symptoms had poorer total c-HRQoL in emotional, school, and physical functioning domains, and their parents experience poor QOL in physical health and psychological domains.
2	Adamou, M., & Jones, S. L. (2020). Quality of life in adult ADHD: A grounded theory approach. *Psychology, 11*(11), 1794–1812. https://doi.org/10.4236/psych.2020.1111113	This study examined QOL of three adults diagnosed with adult ADHD using grounded theory methodology. The interviews & data collection reports show that the participants experienced a lack of a supportive network, labeling, social barriers, & less educational opportunities.
3	Afzali, M., Etemad, K., Kazemi, A., & Rabiei, R. (2019). Cerebral palsy information system with an approach to information architecture: A systematic review. *BMJ Health & Care Informatics*, *26*(1). https://doi.org/10.1136/bmjhci-2019-100055	The systematic review of 39 articles examined long-term complications & excessive costs of CP to conclude that developing a robust CP information system requires deploying principles of information architecture when developing the system. This can improve data structure, content of CP system, data quality, & data sharing.
4	Alenazi, D., Hammad, S., & Mohamed, A. (2020). Effect of autism on parental quality of life in Arar City, Saudi Arabia. *Journal of Family and Community Medicine, 27*(1), 15-22. https://doi.org/10.4103%2Fjfcm.JFCM_157_19	This study described the severity of effect on the domains of the QOL of caregivers of children with ASD & identified the characteristics of caregivers & children associated with impaired QOL. This was done with a cross-sectional study, including 84 parents of children with ASD. Results concluded that less than two-thirds of the caregivers had impaired QOL.
5	Al-Farsi, O. A., Al-Farsi, Y. M., Al-Sharbati, M. M., Al-Adawi, S., Cucchi, A., Essa, M. M., & Qoronfleh, M. W. (2020). Quality of life among caregivers of children with autism spectrum disorders, intellectual disability, and typical development. *Applied Research in Quality of Life*. https://doi.org/10.1007/s11482-020-09880-9	This study sought to investigate the socio-demographic characteristics of caregivers of children with ASD, ID, and TD and to compare their health satisfaction in Oman by employing 220 caregivers of children with ASD, 109 caregivers of children with ID, and 125 caregivers of children with TD. Results concluded that caregivers of children with ASD have poorer QOL than other groups of caregivers.
6	Anixt, J. S., Murray, D. S., Coury, D. L., Kuhlthau, K. A., Eskra, D., Seide, J., Kelly, A., Hess, A., Lipkin, P. H., Law, J. K., Fedele, A., Lannon, C. (2020). Improving behavior challenges and quality of life in the autism learning health network. *Pediatrics (Evanston), 145*(Suppl 1), S20-S29. https://doi.org/10.1542/peds.2019-1895E	A cross-sectional study of children with ASD receiving care at 13 sites. Parent-reported characteristics of children with ASD were collected as outcome measures. Measures aligned with the network's aims of reducing rates of challenging behaviors, improving QOL, & ensuring receipt of recommended health services.

7	Arora, S., Goodall, S., Viney, R., Einfeld, S., MHYPEDD team, & the MHYPEDD team. (2020). Health-related quality of life amongst primary caregivers of children with intellectual disability. *Journal of Intellectual Disability Research, 64*(2), 103-116. https://doi.org/10.1111/jir.12701	This study examined the impact of ID in children (2-12 yrs) on the HRQoL of 634 caregivers using the EQ-5D-5L measure. It was determined that the impact of childhood ID on caregivers' HRQOL across co-morbid diagnostic groups & the risk factors associated with lower HRQOL in this population.
8	Azad, G. F., Dillon, E., Feuerstein, J., Kalb, L., Neely J., & Landa, R. (2020). Quality of life in school-aged youth referred to an autism specialty clinic: A latent profile analysis. *Journal of Autism and Developmental Disorders, 50*(4), 1269-1280. https://doi.org/10.1007/s10803-019-04353-x	Data were from parental report of 476 youth who were scheduled to receive an evaluation at an ASD clinic to examine different profiles of QOL for youth referred to an ASD specialty clinic. The study suggests that screening for QoL, and subsequent assessment of its domains, provides individualized treatment recommendations and enhances the outcomes for children.
9	Bent, S., Wahlberg, J., Chen, Y., Widjaja, F., McDonald M. G., Hendren, R. L. (2020). Quality of life among school-age children with autism: The Oak Hill school outcomes study. *Seminars in Pediatric Neurology, 34*, 100808-100808. https://doi.org/10.1016/j.spen.2020.100808	This paper describes a 2-year cohort study of 29 children attending a specialized school for ASD with quarterly measures of parent-rated QOL as well as parent & teacher measures of behavior & social skills. Study determined the trajectory of change in QOL & predictors of change.
10	Bertelli, M. O., Del Furia, C., Bonadiman, M., Rondini, E., Banks, R., & Lassi, S. (2020). The relationship between spiritual life and quality of life in people with intellectual disability and/or low-functioning autism spectrum disorders. *Journal of Religion and Health, 59*(4), 1996-2018. https://doi.org/10.1007/s10943-019-00891-x	The study mapped international scientific literature to identify the reasons for such inconsideration & the key points for future research & practice implementation. Points are based on a series of complexities, including personal attitude, family members, health & social-care personnel, training, faith & life communities, & even different religions.
11	Brennan, D., McCausland, D., O'Donovan, M. A., Eustace-Cook, J., McCallion, P., & McCarron, M. (2020). Approaches to and outcomes of future planning for family carers of adults with an intellectual disability: A systematic review. *Journal of Applied Research in Intellectual Disabilities, 33*(6), 1221–1233. https://doi.org/10.1111/jar.12742	This systematic review set existing evidence from intervention studies of future care planning for adults with ID. Results concluded there is an urgent need for a more expansive research base that evaluates approaches to supporting adults with ID & their family carers to plan for their futures.
12	Chu, SY, Park, H, Lee, J, Shaharuddin, KKb, Gan, CH. (2020). Self-stigma and its associations with stress and quality of life among Malaysian parents of children with autism. *Child: Care, Health & Development, 4*6(4), 485-494. https://doi.org/10.1111/cch.12771	This study explores the relationship between self-perceived stigmatization (affiliate stigma), stress & QOL among 110 parents of children with ASD using Affiliate Stigma Scale, the Caregiver Burden Inventory, & the CarerQOL scale. Results show that affiliate stigma does not play a big part in stress and QOL.
13	Farajzadeh, A., Maroufizadeh, S., & Amini, M. (2020). Factors associated with quality of life among mothers of children with cerebral palsy. *International Journal of Nursing Practice, 26*(3), e12811-n/a. https://doi.org/10.1111/ijn.12811	In this cross-sectional study, 203 mothers of children with CP were selected using convenience sampling, WHOQOL-BREF, the Beck Depression Inventory, the Caregiver Difficulties Scale, Fatigue Severity Scale. The burden of care, depression, fatigue, and the type of CP, significantly predicted QOL.

14	Ferreira, M. C., Garcia, N. R., Prudente, C. O. M., Ribeiro, M. F. M. (2020). Quality of life of adolescents with cerebral palsy: Agreement between self-report and caregiver's report. *Revista Latino-Americana De Enfermagem, 28*, e3300-e3300. https://doi.org/10.1590/1518-8345.3928.3300	This cross-sectional study from 101 adolescents with CP & 101 caregivers compares the QOL of adolescents with CP by self-report & by the caregiver's report. There was poor agreement between the reports except for physical health domain, so caregivers report should be used cautiously in adolescents capable of self-reporting QOL.
15	Fernández-Ávalos, M.I., Pérez-Marfil, M.N., Ferrer-Cascales, R., Cruz-Quintana, F., Clement-Carbonell, V., Fernández-Alcántara, M. (2020). Quality of life and concerns in parent caregivers of adult children diagnosed with intellectual disability: A qualitative study. I*nternational Journal of Environmental Research and Public Health, 17*(22), 8690. https://doi.org/10.3390/ijerph17228690	This study had parents of adult children with ID evaluated using a semi-structured interview format to carry out an in-depth analysis of the current QOL & concerns of both mothers & fathers of adults diagnosed with ID. The moment of the diagnosis was a reference.
16	Fitzpatrick, S. E., Schmitt, L. M., Adams, R., Pedapati, E. V., Wink, L. K., Shaffer, R. C., Sage, J., Weber, J. D., Dominick K. C., & Erickson, C. A. (2020). Pediatric quality of life inventory (PedsQL) in fragile X syndrome. *Journal of Autism and Developmental Disorders, 50*(3), 1056-1063. https://doi.org/10.1007/s10803-019-04292-7	This study uses QOL data gathered using the Pediatric QOL Inventory (PedsQL) completed online by 364 parents of youth with FXS to evaluate QOL of youth with fragile X syndrome (FXS). Parents reported that their children experienced the highest QoL in Physical functioning and the lowest QoL in Cognitive functioning. Overall, older children with FXS had increase QoL ratings in the domains of School and Cognitive function.
17	Fong, V. C., Gardiner, E., & Iarocci, G. (2020). Can a combination of mental health services and ADL therapies improve quality of life in families of children with autism spectrum disorder? *Quality of Life Research, 29*(8), 2161-2170. https://doi.org/10.1007/s11136-020-02440-6	This study describes the FQOL of 164 caregivers of children diagnosed with ASD (*Beach Center FQOLS & Nisonger Child Behaviour Rating Form*). Results show that service usage type significantly predicted families' satisfaction with their emotional well-being, physical well-being, & disability-related support.
18	Francisco Mora, C., Ibáñez, A., & Balcells-Balcells, A. (2020). State of the art of family quality of life in early care and disability: A systematic review. *International Journal of Environmental Research and Public Health, 17*(19), 7220. https://doi.org/10.3390/ijerph17197220	Study analyzed conceptualization of QOL of families with children with disabilities from 63 past studies. Results identified three tools to measure FQOL in early care.
19	Garrido, D., Carballo, G., & Garcia-Retamero, R. (2020). Siblings of children with autism spectrum disorders: Social support and family quality of life. Q*uality of Life Research, 29*(5), 1193-1202. https://doi.org/10.1007/s11136-020-02429-1	This case–control study explores potential factors that explain the impact of having an older sibling with ASD on several developmental domains, and to test whether these factors could explain their satisfaction on FQoL, using data gathered from 78 unaffected siblings of children with ASD & siblings of children with typical development from 6 to 12 years old.

		Results show significant differences between groups in motor skills, severity of autism, FQOL satisfaction, and social support.
20	Gómez, L. E., Morán, M. L., Alcedo, M. Á., Arias, V. B., Verdugo, M. (2020). Addressing quality of life of children with autism spectrum disorder and intellectual disability. *Intellectual and Developmental Disabilities, 58*(5), 393-408. https://doi.org/10.1352/1934-9556-58.5.393	This study validated a questionnaire to assess QOL of children with ASD & ID. Results showed the KidsLife-ASD Scale is a helpful tool to guide person-centered planning addressed at improving QOL.
21	Hepperlen, R. A., Rabaey, P., & Hearst, M. O. (2020). Evaluating the cross-cultural validity of three family quality of life sub-scales. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 1049-1058. https://doi.org/10.1111/jar.12727	This cross-sectional research used secondary data to extend existing research on the cultural appropriateness of the Beach Center measure, supplying added validity evidence about the internal structure of the scales.
22	Jacobson, D. N. O., Löwing, K., & Tedroff, K. (2020). Health-related quality of life, pain, and fatigue in young adults with cerebral palsy. *Developmental Medicine and Child Neurology, 62*(3), 372-378. https://doi.org/10.1111/dmcn.14413	This paper describes a cross-sectional study of 61 young adults with CP to describe HRQOL, pain, fatigue, & other health variables in young adults with CP. Study explored associations with the Gross Motor Function Classification System – Expanded & Revised (GMFCS-ER) & physical activity.
23	Jacoby, P., Epstein, A., Kim, R., Murphy, N., Leonard, H., Williams, K., Reddihough, D., Whitehouse, A., Downs, J. (2020). Reliability of the quality of life inventory-disability measure in children with intellectual disability. *Journal of Developmental and Behavioral Pediatrics, 41*(7), 534-539. https://doi.org/10.1097/DBP.0000000000000815	QOL Inventory-Disability was administered twice over a 1-month period to 55 primary caregivers of children with ID to assess responsiveness & reproducibility, using the estimates of test-retest reliability for the QOL Inventory-Disability (QI-Disability). Results accounted for changes in child health & parental stress.
24	Jenaro C., Flores N., Gutiérrez-Bermejo B., Vega V., Pérez C., Cruz M. (2020). Parental stress and family quality of life: Surveying family members of persons with intellectual disabilities. *International Journal of Environmental Research and Public Health, 17*(23), 9007. https://doi.org/10.3390/ijerph17239007	The study focused on FQOL of 515 participants who had family members with ID. Study used the Family Adjustment & Adaptation Response framework. Results revealed 49% of participants exhibited parental stress.
25	Jovellar-Isiegas, P., Resa Collados, I., Jaén-Carrillo, D., Roche-Seruendo, L. E., & Cuesta Garcia, C. (2020). Sensory processing, functional performance and quality of life in unilateral cerebral palsy children: A cross-sectional study. *International Journal of Environmental Research and Public Health*, *17*(19), 7116. https://doi.org/10.3390/ijerph17197116	This cross-sectional study analyzed the sensory processing in 29 children with UCP children and 24 typically developing children to examine its relationship with functional performance and QoL using Child Sensory Profile 2 (CSP-2), Pediatric Evaluation of Disability Inventory—Computer Adaptive Test (PEDI-CAT), Kidscreen Questionnaire, (Spanish Version). It was found that children with UCP had difficulty in sensory processing & functional performance compared to controls. & HRQoL perceived by the children were similar in both groups except for physical wellbeing domain.

26	Katsiana, A., Strimpakos, N., Ioannis, V., Kapreli, E., Sofologi, M., Bonti, E., Stiliani, K., Stalikas, A. (2020). Health-related quality of life in children with autism spectrum disorder and children with down syndrome. *Materia Socio-Medica, 32*(2), 93-98. https://doi.org/10.5455/msm.2020.32.93-98	206 caregivers used PedsQL to examine HRQOL in children with ASD & children with Down syndrome and determined that the TD group scored higher than the ASD and Down syndrome group.
27	Koukouriki, E., & Soulis, S. (2020). Self-reported health-related quality of life (HRQOL) and anxiety among Greek school-age siblings of individuals with autism spectrum disorders (ASD) in relation to parental mental health and social support. *Journal of Autism and Developmental Disorders, 50*(8), 2913-2930. https://doi.org/10.1007/s10803-020-04395-6	HRQOL & anxiety were measured in 233 school-age siblings of individuals with ASD & siblings of typically developing children in Greece. Results found elevated anxiety levels & poorer HRQOL than controls.
28	Lawson, L. P., Richdale, A. L., Haschek, A., Flower, R. L., Vartuli, J., Arnold, S. R., & Trollor, J. N. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. *Autism: The International Journal of Research and Practice, 24*(4), 954-967. https://doi.org/10.1177/1362361320908107	This study examined & compared indicators of physical & mental health on QOL among 244 individuals with ASD & 165 individuals without ASD and analyzed the factors contributing to QOL among 93 individuals with ASD after 2yrs. The results show that Subjective QoL was influenced by depressive symptomatology, & psychological well-being influenced all QoL domains except Physical QoL & physical health variables, sleep quality and autonomic symptoms, influenced Physical QoL.
29	Lee, C. E., Burke, M. M., Arnold, C. K., & Owen, A. (2020). Compound sibling caregivers of individuals with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 33*(5), 1069-1079. https://doi.org/10.1111/jar.12729	This study investigated 332 adult siblings of individuals with ID through a national web-based survey. Results found that single & compound sibling caregivers had more positive relationships & conducted greater advocacy & future planning activities.
30	Lee, M. H., Matthews, A. K., Park, C. G., Vincent, C., Hsieh, K., Savage, T. A. (2020). Relationships among parenting stress, health-promoting behaviors, and health-related quality of life in Korean mothers of children with cerebral palsy. *Research in Nursing and Health, 43*(6), 590-601. https://doi.org/10.1002/nur.22074	This study measured health-promoting behaviors using the health-promoting lifestyle profile II on the relationship between parenting stress & HRQOL in 180 mothers of children with CP. The results show that health-promoting behaviors had significant indirect effects between parenting stress and MH QOL, but not between parenting stress and physical health QOL.
31	Lei, X., & Kantor, J. (2020). Social support and family quality of life in Chinese families of children with autism spectrum disorder: The mediating role of family cohesion and adaptability. *International Journal of Developmental Disabilities, 68*(4), 1-8. https://doi.org/10.1080/20473869.2020.1803706	163 caregivers of children with ASD completed the Social Support Rating Scale, Beach Center FQOL Scale, & the Chinese version of Family Adaptability & Cohesion Scale I. Results found that social support had a positive impact on FQOL.
32	Lichtlé, J., Downes, N., Engelberg, A., Cappe, E. (2019-2020). The effects of parent training programs on the quality of life and stress levels of parents raising a child with autism spectrum disorder: A systematic review of the literature. *Review Journal*	A systematic review of 12 studies was conducted to assess the effects of group training programs on the stress levels or QOL of parents of children with ASD,

	of Autism and Developmental Disorders, 7(3), 242-262. https://doi.org/10.1007/s40489-019-00190-x	as well as the implementation fidelity. Results found mindfulness had a positive impact on QOL.
33	Likhitweerawong, N., Boonchooduang, N., & Louthrenoo, O. (2020-2022). Parenting styles, parental stress, and quality of life among caregivers of Thai children with autism. *International Journal of Disability, Development, and Education, 69*(6), 2094-2107. https://doi.org/10.1080/1034912X.2020.1837354	Caregivers of 61 children with & 63 without ASD completed parenting style, parental stress, & QOL questionnaires. Caregivers of children with ASD reported lower authoritative scores, but higher permissive parenting style scores than those of children without ASD.
34	Fitzsimmons, C. L. (2020). *Family Quality of Life in a Canadian Sample* [Dissertation, York University]. http://central.bac-lac.gc.ca/.redirect?app=damspub&id=499f1ade-5aed-4ea6-ba22-4822a1a00d80	This dissertation contains three studies, each evaluating different aspects of the FQOLS-2006 in Canada based on the nine domains.
35	Marsack-Topolewski, C. N. (2020). Quality of life among compound caregivers and noncompound caregivers of adults with autism. *Journal of Gerontological Social Work, 63*(5), 379-391. https://doi.org/10.1080/01634372.2020.1765063	This study compared compound (those providing care for more than one person (n = 112) & noncompound parental caregivers (caring only for an adult with ASD, n = 208) on the domain of psychological QOL with its 6 dimensions as described by WHO's BREF QOL scale. Results found compound caregivers less able to concentrate & with fewer negative feelings than noncompound caregivers.
36	McLaughlin, L., Rapoport, E., Keim, S. A., et al. (2020). Wandering by children with autism spectrum disorders: Impact of electronic tracking devices [ETD] on elopement behavior and quality of life. *Journal of Developmental and Behavioral Pediatrics, 41*(7), 513-521. https://doi.org/10.1097/DBP.0000000000000817	This study focused on the benefits of ETD in 2563 children with ASD who had previously wandered. Results indicated that ETD is promising to help safeguard the well-being of children with ASD & can reduce the emotional toll on families.
37	Mierau, J. O., Kann-Weedage, D., Hoekstra, P. J., Spiegelaar, L., Jansen, D. E. M., Vermeulen, K. M., Reijneveld, S. A., van den Hoofdakker, B. J., Buskens, E., van den Akker-van Marle, M. E., Carmen D. Dirksen & Annabeth P. Groenman. (2020). Assessing quality of life in psychosocial and mental health disorders in children: A comprehensive overview and appraisal of generic health related quality of life measures. *BMC Pediatrics, 20*(1), 329-329. https://doi.org/10.1186/s12887-020-02220-8	This study provided an overview of 22 generic QOL instruments suitable for economic evaluations in children with mental health problems. A systematic search into the psychometric quality of these instruments found 195 suitable papers, of which 30 assessed psychometric quality in child and adolescent mental health. However, none were perfect for use in economic evaluation of child & adolescent mental health care.
38	Musiyenko, O. V., Chopyk, R. V., & Kizlo, N. B. (2020). Influence of swimming on sensory functioning, quality of life and behavior of children with autism. *Health, Sport, Rehabilitation, 6*(3), 60-69. https://doi.org/10.34142/HSR.2020.06.03.07	This study found that swimming as an adaptive physical education had a positive influence on the behaviors of 3 children with ASD. Findings indicate that swimming reduced aggression, frequency of stereotyped movements, and opposition, while improving emotional state, willpower, coordination, and dexterity, as well as QOL that was measured by the EQ-5D-5L.
39	Parsons, D., Cordier, R., Lee, H., Vaz, S. (2020). Stress, coping, and quality of life in families with a child with ASD living	This study explored whether regionality was associated with differing stress levels, coping, QOL, & daily routines for 278 parents & families of a child

	regionally. *Journal of Child and Family Studies, 29*(2), 546-558. https://doi.org/10.1007/s10826-019-01585-4	with ASD in a cross-sectional survey. Results indicate that residing in a geographically LDP area in Western Australia has a small association with preferred coping style preference. There was no association between stress levels, QOL, or daily routines for parents who have a child with ASD.
40	Renford, N. G., Arulappan, J., Thomas, K. D., Karuppiah, K. M., Chinnathambi, K., Thangaswamy, G. C. (2020). Quality of life of caregivers of children with autism spectrum disorder in Tamil Nadu, South India. *International Journal of Nutrition, Pharmacology and Neurological Diseases, 10*(2), 57-64. https://squ.pure.elsevier.com/en/publications/quality-of-life-of-caregivers-of-children-with-autism-spectrum-di	The QOL of 120 caregivers of children with ASD was evaluated using the WHOQoL-BREF. Results indicate the need for sustainable need-based interventions to improve caregiver QOL.
41	Sheridan, C., OMalley-Keighran, M., & Carroll, C. (2020). What are the perspectives of adolescents with down syndrome about their quality of life? A scoping review. *British Journal of Learning Disabilities, 48(2)*, 98-105. https://doi.org/10.1111/bld.12299	This study revolved around QOL assessment of adolescents with Down syndrome. Results concluded that friends, family, & independence are important to adolescents with Down syndrome.
42	Singh, N. N., Lancioni, G. E., Medvedev, O. N., Hwang, Y., Myers, R. E., & Townshend, K. (2020). Using mindfulness to improve QOL in caregivers of individuals with I/DD and ASD. *International Journal of Developmental Disabilities, 66*(5), 370-380. https://doi.org/10.1080/20473869.2020.1827211	To study the benefits of mindfulness, 216 professional caregivers were randomized into three treatment groups 1) mindfulness; 2) psychoeducation, & 3) in-service training-as-usual. The effects of this training on the caregivers' QOL were assessed in terms of perceived stress, compassion satisfaction, compassion fatigue, & symptoms of depression after 32 weeks of implementation. Perceived stress, burnout, and secondary traumatic stress decreased significantly in the mindfulness group (#1), followed by psychoeducation group (#2), but not in the in-service training-as-usual group (#3).
43	Snapp, E., Ketcheson, L., Martin, J., & Centeio, E. (2020). Enhancing quality of life for children with intellectual and developmental disabilities. *International Journal of Disabilities Sports & Health Sciences*, 33–41. https://doi.org/10.33438/ijdshs.713634	This study explores the impact of fundamental motor skill (FMS) interventions on the QOL of 10 children with IDD using the Pediatric QOL Scale 4.0 & visual analysis. Results showed FMS interventions improved social & emotional function of kids with IDD & highlighted need for longitudinal research on FMS' potential in QOL improvement.
44	Stone, M. M., Kash, S., Butler, T., Callahan, K., Verdugo, M. A., Gómez, L. E. (2020). Validation of English language adaptations of the Kidslife and San Martin scales for assessing quality of life with individuals on the autism spectrum receiving residential care. *Journal of Developmental and Physical Disabilities, 32*(1), 131-154. https://doi.org/10.1007/s10882-019-09686-0	This study showed that English translations of the San Martín & KidsLife provided reliable & valid estimates of QOL for individuals with concurrent ASD, IDD, & moderate to profound support needs.
45	Ten Hoopen, L. W., de Nijs, Pieter F. A., Duvekot, J., Greaves-Lord, K., Hillegers, M. H. J., Brouwer, W. B. F., Hakkaart-van Roijen, L. (2019-2020). Children with an autism spectrum	This study investigated HRQOL & care-related QOL in clinically referred children with an ASD, & their primary & secondary caregivers, using the EuroQol

	disorder and their caregivers: Capturing health-related and care-related quality of life. *Journal of Autism and Developmental Disorders, 50*(1), 263-277. https://doi.org/10.1007/s10803-019-04249-w	five-dimensional (EQ-5D) & the CarerQol questionnaires. HRQoL & CarerQol reports of primary caregivers & children were correlated.
46	Waheed, A., Khan, M. J., & Khurshid, M. (2020). Effect of behavioral problems of children with autism on their mother's quality of life. *Pakistan Armed Forces Medical Journal, 70*(6), 1666-70. https://doi.org/10.51253/pafmj.v70i6.3386	This study indicated that QOL of mothers has a significant negative relationship with their children's ASD related behavioral problems through QOL (WHO Quality of life scale -BREF) & behavior problems of children with ASD (Childhood Autism Rating Scale-CARS). Participants included (n = 100) parents of children with ASD & the children themselves.
47	Wakimizu, R., Fujioka, H., Nishigaki, K., & Matsuzawa, A. (2020). Quality of life and associated factors in siblings of children with severe motor and intellectual disabilities: A cross-sectional study. *Nursing and Health Sciences, 22*(4), 977-987. https://doi.org/10.1111/nhs.12755	This study examined QOL & its associated factors in 789 siblings of children with severe motor & ID in Japan. Results found there is a relationship with the child with a disability & siblings' QOL.
48	Zeng, S., Hu, X., Zhao, H., Stone-MacDonald, A. S. Examining the relationships of parental stress, family support and family quality of life: A structural equation modeling approach. *Research in Developmental Disabilities 96*(2020): 103523. https://doi.org/10.1016/j.ridd.2019.103523	This study examined the interrelation of parental stress, family support, & FQOL using a sample of 226 parents of children with ASD, who completed the Beach Center FQOLS & the Family Support Scale for children with ASD

	2021	**Summary of Work**
1	Ademosu, T., Ebuenyi, I., Hoekstra, R. A., Prof, M. P., Salisbury, T. (2021). Burden, impact, and needs of caregivers of children living with mental health or neurodevelopmental conditions in low-income and middle-income countries: A scoping review. *The Lancet Psychiatry*, *8*(10), 919-928. https://doi.org/10.1016/s2215-0366(21)00207-8	Scoping review indicated that caregivers commonly described reduced QOL. They attributed QOL to their children's mental or neurodevelopmental condition. Additional reports of family disruption, caregiver psychological distress, & financial hardship were discussed.
2	Arnaud, C., Duffaut, C., Fauconnier, J., Schmidt, S., Himmelmann, K., Marcelli, M., Pennington, L., Alvarelhão, J., Cytera, C., Rapp, M., Ehlinger, V., Thyen, U. (2021). Determinants of participation and quality of life of young adults with cerebral palsy: Longitudinal approach and comparison with the general population–SPARCLE 3 study protocol. *BMC Neurology*, *21*(1), 1-13. https://doi.org/10.1186/s12883-021-02263-z	The SPARCLE3 study was used to investigate impact of environment on participation & QOL of young adults with CP, to determine predictors of successful young adulthood in educational, professional, health, & social fields, & to compare QOL & frequency of participation in social, work & recreational activities with the general population.
3	Asahar, S. F., Malek, K. A., & Isa, M. R. (2021). Quality of life and child's autism-specific difficulties among Malaysian main caregivers: A cross-sectional study. *International Journal of Environmental Research and Public Health*, *18*(18), 9861. https://doi.org/10.3390/ijerph18189861	Cross-sectional study on QOL of 116 caregivers of children with autism measured using the QOL in Autism Questionnaire. QOL was significantly associated with staying in an apartment & receiving caregiver training session. Caregiver perceptions of child's autism-specific difficulties were associated with receipt of practical help (maid/ grandparent) to care for child & health of caregiver (asthma).
4	Ben-Dor Cohen, M., Eldar, E., Maeir, A., & Nahum, M. (2021). Emotional dysregulation (ED) and health-related quality of life (HRQoL) in young adults with ADHD: A cross-sectional study. *Health and Quality of Life Outcomes, 19*(1). https://doi.org/10.1186/s12955-021-01904-8	This cross-sectional study examined 63 adults with ADHD & 69 controls to measure HRQoL using the Adult ADHD QOL Scale & to measure ED through the Self-Report Wender-Reimherr Adult Attention Deficit Disorder Scale & the Difficulties in Emotion Regulation Scale. Results showed both HRQoL & ED to be lower for ADHD group & that ED balanced the effect of ADHD symptoms on patients.
5	Cameranesi, M., Shooshtari, S., Dubé, C., McCombe, L. (2021). Quality of life of persons with severe or profound intellectual and developmental disabilities transitioning into community from a complex care residence in Canada. *Journal on Developmental Disabilities*, *26*(1), 1-17. https://oadd.org/wp-content/uploads/2021/05/V26-N1-19-320-Cameranesi-et-al-v2.pdf	The goal of this research study was to measure changes in the QOL of adults with profound intellectual & multiple disabilities (PIMD) & complex care needs following their transition from a large institutional residence to smaller community homes in Central Canada. Results provided evidence of improved QOL for persons with PIMD following deinstitutionalization.
6	Cankurtaran, D., Tezel, N., Yildiz, S. Y., Akyuz, E. U. (2021). Evaluation of the effects of the COVID-19 pandemic on children with cerebral palsy, caregivers' quality of life, and caregivers' fear of COVID-19 with telemedicine. *Irish Journal of Medical Science (1971-)*, *190*(4), 1473-1480. https://doi.org/10.1007/s11845-021-02622-2	This study investigated the impact of the novel coronavirus (COVID-19) pandemic on the use of health & rehabilitation services & the general & physical health of children with CP. Results concluded that more attention should be given to telerehabilitation & telemedicine services of the clinicians who treat children with CP.

7	Celik, H., Acikel, S. B., Ozdemir, M. A. F., Aksoy, E. Oztoprak, U., Ceylan, N., Yuksel, D. (2021). Evaluation of the clinical characteristics of children with autism spectrum disorder and epilepsy and the perception of their parents on quality of life. *Epilepsy Research*, *172*, 106599. https://doi.org/10.1016/j.eplepsyres.2021.106599	ASD is among the serious clinical pictures of early childhood, & its main symptoms are qualitative dysfunction in social interactions with impairment of verbal & nonverbal communication & limitations in interests & activities. Results concluded many psychiatric & medical conditions can co-occur with ASD.
8	Chiang, S., Moss, R., Meskis, M. A., Vogel-Farley, V., Sullivan, J. E., Patel, A. D., & Rao, V. R. (2021). Impact of intellectual and developmental disability on quality-of-life priorities in adults with epilepsy. *Epilepsy & Behavior, 123*, 108282. https://doi.org/10.1016/j.yebeh.2021.108282	This cross-sectional study sought to identify HRQOL priorities in adults with IDD-E and in caregivers, and to compare results with those of epileptic adults without IDD. 65 adults with IDD-E and 134 adults with just epilepsy were surveyed. HRQOL was reportedly lower for those with IDD-E than without. HRQOL priorities were found to include seizure burden, anti-seizure medication side effects, & family impact, among others.
9	Correia, R. A., & Seabra-Santos, M. J. (2021). “I would like to have a normal brother but I’m happy with the brother that I have:” A pilot study about intellectual disabilities and family quality of life from the perspective of siblings. *Journal of Family Issues*, *43*(12), 3148-3167. https://doi.org/10.1177/0192513X211042845	This study explored experiences as an adolescent or adult sibling of a person with ID to understand perceptions of and their siblings about QOL as a sibling & about FQOL. Six in-depth interviews of siblings indicated that the experience of a sibling is positive, & the acceptance process is of extreme importance.
10	Couderc, S., Cousson-Gélie, F., Pernon, E., Porro, B., Miot, S. and Baghdadli, A. (2021). Burnout among direct support workers of adults with autism spectrum disorder and intellectual disability. *Scandinavian Journal of Caring Sciences*. https://doi.org/10.1111/scs.13008	DSWs accompanying ASD-ID adults (This study focused on 125) answered four participants questionnaire. Results indicated the burnout process of ASD-ID DSWs may require the assessment of the organizational characteristics linked to the QOL of the DSWs & the recognition of their specific needs when facing difficulties.
11	Davis, A. O., Olagbegi, O. M., Orekoya, K., Adekunle, M., Oyewole, O. O., Adepoju, M., & Soetan, O. (2021). Burden and quality of life of informal caregivers of children with cerebral palsy. *Rev Rene, 22*, e61752. https://doi.org/10.15253/2175-6783.20212261752	This study investigated the QOL and burden of 109 caregivers of children with CP. Results indicated that about 1/3 of the caregivers had high strain, with their jobs being the main source. However, 2/3 of the caregivers who were assessed reported high personal wellbeing.
12	Fereidouni, Z., Kamyab, A. H., Dehghan, A., Khiyali, Z., Ziapour, A., Mehedi, N., Toghroli, R. (2021). A comparative study on the quality of life and resilience of mothers with disabled and neurotypically developing children in Iran. *Heliyon*, *7*(6), e07285. https://doi.org/10.1016/j.heliyon.2021.e07285	The study investigated how child’s disability status affects maternal QOL (n = 240). Results indicated QOL of mothers of children with disabilities was lower than that of mothers of typically developing children, but they had similar resiliency.
13	Friedman, C. (2021). The COVID-19 pandemic and quality of life outcomes of people with intellectual and developmental disabilities. *Disability and Health Journal*, *14*(4), 101117. https://doi.org/10.1016/j.dhjo.2021.101117	This study explored the impact of the COVID-19 pandemic on the QOL outcomes of PWIDD through a secondary analysis of data gathered from 2284 interviews conducted using Personal Outcome Measures® from 2019 to 2020. Results found COVID-

		19 pandemic has negatively hindered the QOL outcomes of PWIDD in many different areas.
14	Hassanein, E. E., Adawi, T. R., Johnson, E. S. (2021). Social support, resilience, and quality of life for families with children with intellectual disabilities. *Research in Developmental Disabilities*, *112*, 103910. https://doi.org/10.1016/j.ridd.2021.103910	This study focused on 88 mothers who completed the the Brief Resilience Scale, 2-Way Social Support Scale, & Beach Center FQOLS. Results showed giving & receiving social support accounted for 62% variance in FQOL, while resilience was not a significant predictor.
15	Heras, I., Amor, A. M., Verdugo, M. Á., & Calvo, M. I. (2021). Operationalisation of quality of life for students with intellectual and developmental disabilities to improve their inclusion. *Research in Developmental Disabilities*, 119, 104093. https://doi.org/10.1016/j.ridd.2021.104093	This study aimed to assess education outcomes & develop a QOL assessment tool for students with IDD through a four-round Delphi study, which 14 educational professionals participated in. Results showed importance of including the following 4 criteria in the QOL assessment: suitability, importance, observability, & sensitivity.
16	Iovino, E. A., Caemmerer, J., & Chafouleas, S. M. (2021). Psychological distress and burden among family caregivers of children with and without developmental disabilities six months into the COVID-19 pandemic. *Research in Developmental Disabilities*, *114*, 103983. https://doi.org/10.1016/j.ridd.2021.103983	This study focused on a 6-month follow-up on caregiver burden & psychological distress among 407 caregivers of children with ASD &/or ADHD during COVID-19 pandemic. Results indicated that caregivers of children with ASD/ADHD faced more challenges but were more resilient to COVID-19 challenges than caregivers of typically developing children.
17	Kim, J., Kim, H., Park, S., Yoo, J., Gelegjamts, D. (2021). Mediating effects of family functioning on the relationship between care burden and family quality of life of caregivers of children with intellectual disabilities in Mongolia. *Journal of Applied Research in Intellectual Disabilities*, *34*(2), 507-515. https://doi.org/10.1111/jar.12814	The study evaluated how family functioning mediated the relationship between care burden & FQOL of caregivers of children with IDD. using multiple linear regression analyses. Findings suggest that family functioning should be considered when developing a social support interventions for children with IDD.
18	Kobosko, J., Ganc, M., Paluch, P., Jedrzejczak, W. W., Fludra, M., Skarzynski, H. (2021). Developmental outcomes of young deaf children and the self-perceived parental role of their hearing mothers. *International Journal of Pediatric Otorhinolaryngology*, *141*, 110517. https://doi.org/10.1016/j.ijporl.2020.110517	The study found predictors of global psychomotor development in young deaf children who had a cochlear implant (CI; n = 36), or were CI candidates (n = 28), using several methods. The use of CI, maternal investment in parenting, & family's community participation were important determinants of the global psychomotor development of a young deaf child.
19	Leader, G., Flynn, C., O'Rourke, N., Coyne, R., Caher, A., & Mannion, A. (2021). Comorbid psychopathology, challenging behavior, sensory issues, adaptive behavior and quality of life in children and adolescents with autism spectrum disorder. *Developmental Neurorehabilitation*, *24*(6), 397-407. https://doi.org/10.1080/17518423.2021.1898058	The study investigated differences between 133 children and adolescents on the autism spectrum with no-mild, moderate and severe comorbid psychopathology (Evaluation tools: Autism Spectrum Disorder-Comorbid for Children, Behavior Problems Inventory-Short Form, *Pediatric Quality of Life Inventory*, Vineland Adaptive Behavior Scales, Social Communication Questionnaire, Short Sensory Profile, and Behavioral/Educational Interventions and Complementary/Alternative Medicine Interventions of the Autism Treatment Network Registry Parent Baseline Assessment). The study reports exacerbated sensory issues, lower QOL scores and higher

		intellectual disability with higher levels of comorbid psychopathological conditions.
20	Leader, G., Barrett, A., Ferrari, C., Casburn, M., Maher, L., Naughton, K., Arndt, S., Mannion, A. (2021). Quality of life, gastrointestinal symptoms, sleep problems, social support, and social functioning in adults with autism spectrum disorder. *Research in Developmental Disabilities*, *112*, 103915. https://doi.org/10.1016/j.ridd.2021.103915	This study investigated the relationship between sleep problems, gastrointestinal symptoms, social functioning, autism traits, & social support on QOL in 107 adults with ASD. Results concluded that GI symptoms & sleep problems are common comorbid conditions in adults with ASD.
21	Lee, A., Knafl, K., & Van Riper, M. (2021). Family variables and quality of life in children with down syndrome: A scoping review. *International Journal of Environmental Research and Public Health*, *18*(2), 419. https://doi.org/10.3390/ijerph18020419	This review article from 2314 studies identified the family & child QOL variables that have been studied in relation to one another in children with Down syndrome. Results found that the relationship between family variables & child QOL rarely was the primary focus of the study.
22	Lei, X., & Kantor, J. (2021). Correlates of social support and family quality of life in Chinese caregivers of children with autism spectrum disorder. *International Journal of Disability, Development and Education*, 1-14. https://doi.org/10.1080/1034912X.2021.1940881	This survey research study focused on perceptions of social support & family functioning among 167 caregivers of children with ASD from Sichuan province in China. Findings describe the importance of different types of social support & could how they can be used to develop a targeted support service for families that have children with ASD to improve FQOL.
23	Liang, S. H. Y., Lee, Y. C., Kelsen, B. A., Chen, V.C. (2021). Health-related quality of life in mothers of children with attention deficit hyperactivity disorder in Taiwan: The roles of child, parent, and family characteristics. *Research in Developmental Disabilities*, *113*, 103944. https://doi.org/10.1016/j.ridd.2021.103944	This study investigated the impact of children's diagnosis of ADHD, children's & maternal psychopathology, significant sociodemographic variables of the children, parents, & family on HRQOL of mothers of children with & without ADHD (n = 257 and n = 324) in Taiwan. Mothers of children with ADHD had worse HRQOL in all four domains (measured using WHOQOL-BREF) compared with mothers of typically developing children. Maternal depression and perceived family support was associated with HRQOL of mothers, after controlling for several familial, parental & child variables.
24	Lücke, C., Jenkner, C., Graf, E., Matthies, S., Borel, P., Sobanski, E., Alm, B., Rösler, M., Retz, W., Jacob, C., Colla, M., Huss, M., Jans, T., Kis, B., Abdel-Hamid, M., Müller, H. H. O., Lam, A. P., Berger, M., Tebartz van Elst, L., & Philipsen, A. (2021). Long-term improvement of quality of life in adult ADHD – results of the randomized multimodal COMPAS trial. *International Journal of Mental Health, 50*(3), 250–270. https://doi.org/10.1080/00207411.2021.1910172	This study aims to investigate treatments of ADHD involving long-term improvements of QOL, analyzing 419 ADHD patients in the process. COMPAS was found to exhibit long-term improvements of QOL after treatment regardless of medication, proving to be the most efficient treatment.
25	Luitwieler, N., Luijkx, J., Salavati, M., Van der Schans, C. P., Van der Putten, A. J., & Waninge, A. (2021). Variables related to the quality of life of families that have a child with severe to profound intellectual disabilities: A systematic review. *Heliyon*, *7*(7), e07372. https://doi.org/10.1016/j.heliyon.2021.e07372	Systematic review gained a better understanding of variables related to the FQOL of families that have a child with SPID & variables related to the FQOL of families that have a child with IDD.

26	Pecor, K. W., Barbayannis, G., Yang, M., Johnson, J., Materasso, S., Borda, M., & Ming, X. (2021). Quality of life changes during the COVID-19 pandemic for caregivers of children with ADHD and/or ASD. *International Journal of Environmental Research and Public Health*, *18*(7), 3667. https://doi.org/10.3390/ijerph18073667	This study contrasted QOL for caregivers of children with ADHD &/or ASD, before & during the pandemic, compared to caregivers of neurotypical (NT) children. Results showed that caregivers of ADHD &/or ASD children reported lower QOL, both before & during the pandemic, in comparison to caregivers of NT children.
27	Peñuelas-Calvo, I., Palomar-Ciria, N., Porras-Segovia, A., Miguélez-Fernández, C., Baltasar-Tello, I., Perez- Colmenero, S., Delgado-Gómez, D., Carballo, J. J., Baca-García, E. (2021). Impact of ADHD symptoms on family functioning, family burden and parents' quality of life in a hospital area in Spain. *The European Journal of Psychiatry*, *35*(3), 166-172. https://doi.org/10.1016/j.ejpsy.2020.10.003	This study evaluated 74 parents of children diagnosed with ADHD through electronic self-administered scales. Results suggested that the severity of ADHD has a negative impact on parents' QOL & family functioning in inattention & combined subtypes.
28	Pett, M. A., Guo, J., Cardell, B., Johnson, E. P., Guerra, N., & Clark, L. (2021). Psychometric properties of a brief self-reported health-related quality of life measure (HRQoL-IDD) for persons with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities, 34*(3), 877-890. https://doi.org/10.1111/jar.12831	224 volunteers completed QOL quality of life items developed with extensive input from persons with intellectual and developmental disabilities, family members/caregivers, and providers. The 5-point Likert scale format with visual images of fluid-filled cups represented the range of responses. An exploratory & unrestricted analysis of 16 items from HRQoL-IDD taken by 224 volunteers indicated it as a promising measure in community-based settings for persons with mild to moderate support related to IDD. This was due to internal consistency & stability of responses when evaluating psychometric properties.
29	Ramamurthy, D., Rao, A., & Kumar, U. (2021). Quality of life in caregivers of children with developmental delay – A case–control study. *International Journal of Health & Allied Sciences, 10*(1), 48. https://doi.org/10.4103/ijhas.ijhas_146_20	This case-control study examined QOL of caregivers of children with developmental delay by assessing 30 children with delays & 30 with none & using WHOQOL-BREF. Results found 50% of cases were severe delays with caregivers having poor physical & social QOL, while controls had higher QOLs overall.
30	Reddihough, D., Leonard, H., Jacoby, P., Kim, R., Epstein, A., Murphy, N., Reid, S., Whitehouse, A., Williams, K., Downs, J. (2021). Comorbidities and quality of life in children with intellectual disability. *Child: Care, Health and Development*, *47*(5), 654-666. https://doi.org/10.1111/cch.12873	In this study, 447 primary caregivers of children with an ID reported on their child's medical comorbidities & the extent to which they perceived their child's medical needs had been met in a cross-sectional observational study. Results found evaluation & management of pain & sleep disturbance continue to be high priorities in improving QOL of young people with IDs.
31	Sáez-Suanes, G. P., & Álvarez-Couto, M. (2021). Factors associated with quality of life in adults with autism spectrum disorder: A systematic review. *Review Journal of Autism and Developmental Disorders.* https://doi.org/10.1007/s40489-021-00254-x	A systematic review was executed following the PRISMA protocol to assess the QOL of adults with ASD through analysis of eleven different articles. Results showed lower levels of QOL in adults with ASD than in general population, emphasizing need for adapting concept of QOL to conditions & realities of ASD.

32	Shogren, K. A., Bonardi, A., Cobranchi, C., Krahn, G., Murray, A., Robinson, A., Havercamp, S. M., & The Nisonger RRTC on Health and Function. (2021). State of the field: The need for self-report measures of health and quality of life for people with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 18*(4), 286-295. https://doi.org/10.1111/jppi.12386	A literature-informed overview of the state of the field of self-reported tools used by adults with IDD when measuring their physical health & QOL. The article addresses 1) definitions of key constructs; 2) literature review of existing/emerging practices in assessment including overuse of proxy-respondents; 3) emerging directions on cognitive accessibility/ universal design 4) action steps to incorporate self-reporting of health outcomes by people with IDD in research, policy, & practice.
33	Schwartz, I. S., & Kelly, E. M. (2021). Quality of life for people with disabilities: Why applied behavior analysts should consider this a primary dependent variable. *Research and Practice for Persons with Severe Disabilities*, *46*(3), 159-172. https://doi.org/10.1177/15407969211033629	In this article, the authors proposed that improved QOL should be the ultimate outcome for consumers receiving behavioral interventions. They then explored definitions of QOL & suggested some strategies that behavior analysts can apply to modify practices to more clearly center QOL as an outcome variable.
34	Skaletski, E. C., Bradley, L., Taylor, D., Travers, B. G., & Bishop, L. (2021). Quality of life discrepancies among autistic adolescents and adults: A rapid review. A*merican Journal of Occupational Therapy*, 75(3), 7503180090p1. https://doi.org/10.5014/ajot.2021.046391	This study investigated the self-reported differences in QOL of adolescents & adults with and without autism by reviewing 27 quantitative articles published between 2010-2020. Those with autism reported lower QOL than peers. Interventions improved QOL of those with autism.
35	Tomaszewski, B., Savage, M. N., & Hume, K. (2021). Examining physical activity and quality of life in adults with autism spectrum disorder and intellectual disability. *Journal of Intellectual Disabilities*, *1*, 14. https://doi.org/10.1177/17446295211033467	This study examined the relationship between physical activity, using an activity tracker, & QOL in adults with ASD & ID through 38 adults with ASD & ID. Participants wore a Fitbit Flex 2® activity tracker for 1 week, & completed the QOL Questionnaire. Results indicated increased average daily step count was significantly associated with QOL.
36	Vaz, S., Thomson, A., Cuomo, B., Falkmer, T., Chamberlain, A., & Black, M. H. (2021). Co-occurring intellectual disability and autism: Associations with stress, coping, time use, and quality of life in caregivers. *Research in Autism Spectrum Disorders*, *84*, 101765. https://doi.org/10.1016/j.rasd.2021.101765	This study compared caregiver stress & time use among 61 children with ASD & IDD & 216 children with ASD. Caregivers reported greater stress & reported different time use patterns in meal preparation, socialization with friends, & respite care.
37	Vidart d'Egurbide Bagazgoïtia, N., Ehlinger, V., Duffaut, C., Fauconnier, J., Schmidt-Schuchert, S., Thyen, U., Himmelmann, K., Marcelli, M., & Arnaud, C. (2021). Quality of life in young adults with cerebral palsy: A longitudinal analysis of the SPARCLE study. *Frontiers in Neurology*, 12. https://doi.org/10.3389/fneur.2021.733978	A longitudinal study was conducted to examine the QOL of 164 young adults living with CP who'd previously participated in the SPARCLE study, measured through age-appropriate instruments & linear mixed-effect models to estimate how QOL is influenced by factors like pain & severity of impairment, which were found to be direct influences. Results also indicated that QOL & psychological wellbeing decreased from childhood to

		adulthood, while QOL in social relationships increased.
38	Wang, R., Liu, Q., & Zhang, W. (2022). Coping, social support, and family quality of life for caregivers of individuals with autism: Meta-analytic structural equation modeling. *Personality and Individual Differences*, *186*, 111351. https://doi.org/10.1016/j.paid.2021.111351	This study used the meta-analysis structural equation modeling (MASEM) method of 29 studies (N = 4864) to explore the relationship between coping (positive & negative), social support, & FQOL for caregivers of individuals with ASD. Results found caregivers with spouses were more likely to reduce social support when they adopted negative coping than caregivers without spouses (p = .022).
39	Whitehouse, A. J. O., Jacoby, P., Reddihough, D., Leonard, H., Williams, K., & Downs, J. (2021). The effect of functioning on quality of life inventory-disability measured quality of life is not mediated or moderated by parental psychological distress. *Quality of Life Research*, *30*(10), 2875-2885. https://doi.org/10.1007/s11136-021-02855-9	This study investigated whether caregiver psychological distress mediates or moderates the effects of impairment on their ratings of QOL in children with IDD. Results found caregiver psychological distress did not mediate or moderate the relationship between the level of functional abilities & QOL in children with IDD.
40	Williams, K., Jacoby, P., Whitehouse, A., Kim, R., Epstein, A., Murphy, N., Reid, S., Reddihough, D., Downs, J. (2021). Functioning, participation, and quality of life in children with intellectual disability: An observational study. *Developmental Medicine & Child Neurology*, *63*(1), 89-96. https://doi.org/10.1111/dmcn.14657	This study examined the relationship between social support & family functioning through the Chinese version of the Family Adaptability & Cohesion Scale. Results showed the importance of different types of social support & could be used to develop a targeted support service for families that have children with ASD to improve FQOL.
41	Wos, K., Kamecka-Antczak, C., & Szafrański, M. (2021). Remote support for adults with intellectual disability during COVID-19: From a caregiver's perspective. *Journal of Policy and Practice in Intellectual Disabilities*, *18*(4), 279-285. https://doi.org/10.1111%2Fjppi.12385	This research project explored the experiences of parents of adults with ID in relation to remote support provided by public support agencies through semi-structured individual interviews with caregivers of people with ID. Results found difficulties of parents in balancing professional, domestic, & supporting tasks.
42	Ying, K., Rostenberghe, H. V., Kuan, G., Mohd Yusoff, M.H.A., Ali S. H., Yaacob, N. S. (2021). Health-related quality of life and family functioning of primary caregivers of children with cerebral palsy in Malaysia. *International Journal of Environmental Research and Public Health*, *18*(5), 2351. https://doi.org/10.3390/ijerph18052351	This study examined the overall impact of caregiving for children with CP on primary caregivers' HRQOL & family functioning. The study identified potential factors associated with primary caregivers' HRQOL & family functioning through the cross-sectional study involving 159 primary caregivers of children with CP. Results found stakeholders enhanced the QOL of primary caregivers.

	2022	**Summary of Work**
1	Ahmed, M. G. A. E., Felemban, E. M., & El-slamoni, M. A. E. F. A. (2022). A comparative study: Quality of life, self-competence, and self-liking among the caregivers of children with attention deficit hyperactivity disorder and other non-ADHD children. *Middle East Current Psychiatry*, *29*(1), 1-11. https://doi.org/10.1186/s43045-022-00189-x	This cross-sectional study compared QOL, self-competence, & self-liking among 216 caregivers of children with and without ADHD. Caregivers of children with ADHD were found to have fair levels of QOL, self-liking, & self-competence compared to those caring for children without ADHD.
2	Alnahdi, G.H., Alwadei, A., Woltran, F., Schwab, S. (2022) Measuring family quality of life: Scoping review of the available scales and future directions. *International Journal of Environmental Research Public Health 2022, 19*, 15473. https://doi.org/10.3390/ijerph192315473	The study conducted a review of 3948 studies measuring FQOL individuals with IDD, to identify the most used scales & their psychometric properties. Results did not find a common scale.
3	Borilli, M. C., Germano, C. M. R., de Avó, L. R. D. S., Pilotto, R. F., & Melo, D. G. (2022). Family quality of life among families who have children with mild intellectual disability associated with mild autism spectrum disorder. *Arquivos de neuro-psiquiatria*, *80*(4), 360–367. https://doi.org/10.1590/0004-282X-ANP-2020-0537	This article examined the FQoL among families of children with mild intellectual disability and ASD in Brazil using the Barthel index and Beach Center FQoL scale. FQOL predictors-included parents' marital status, family income, religious practices, and the child's communication abilities. They concluded that strong family interaction and parental care helped maintain FQoL, while enhancing emotional and material conditions could further improve it for these families.
4	Boland, G., & Guerin, S. (2022). Connecting locally: The role of adult siblings in supporting the social inclusion in neighbourhoods of adults with intellectual disability. *British Journal of Learning Disabilities*, *50*(3), 327-340. http://doi.org/10.1111/bld.12404	This multiple dyad case study explores the experiences of nondisabled siblings of offering support for local engagement and siblings with intellectual disability being supported by their brother or sister. The role of adult siblings in supporting engagement as local connectors has untapped potential as a resource that will contribute to social inclusion in neighbourhoods, however, a range of factors exist that influence the nature of that involvement.
5	Boland, G., & Guerin, S. (2022). Connecting locally: An examination of the role of service providers in supporting the social inclusion of adults with intellectual disabilities in their neighbourhoods. *Journal of Policy and Practice in Intellectual Disabilities*, *19*(3), 288–299. https://doi.org/10.1111/jppi.12419	This national survey of CEOs/service leaders examined the role of service providers in supporting social inclusion in neighbourhoods of adults with intellectual disabilities. Close to two-thirds did not have an organisational policy in place regarding social inclusion. This study is rich in policy, practice, and research recommendations that will positively influence frontline services.
6	Bhatt, N., Canella, J., & Gentile, J. P. (2022). Brief review: Psychological health and life quality of cerebral palsy. *Theory and Clinical Practice in Pediatrics, 4*(1), 102–105. https://doi.org/10.25082/tcpp.2022.01.001	This study examines QOL of those with CP, including all ages. Results showed that most patients reported psychosocial and mental health issues, & that interventions should be

		reconsidered & adapted to address QOL of CP patients, too.
7	Bogja Jeoung. (2022). Quality of life and health-promoting lifestyles for parents of children with intellectual and developmental disabilities. *Journal of Exercise Rehabilitation,* 18(6), 361–368. https://doi.org/10.12965/jer.2244450.225	The study analyzes the relationship between QOL and Korean version of the health-Promoting Lifestyle Profile-II (HPLP-II) across six subfactors (spiritual growth, health responsibility, exercise, nutrition, interpersonal relations, stress management) in 254 parents of children with IDD. The authors report that HPLP-II subfactors were strong predictors of QoL and so they recommend including HPLP to improve QoL in parents of children with IDD
8	Bolbocean, C., Andújar, F. N., McCormack, M., Sutur, B., Holder Jr, J. L. (2022). Health-related quality of life in pediatric patients with syndromic autism and their caregivers. *Journal of Autism and Developmental Disorders*, *52*(3), 1334-1345. https://doi.org/10.1007/s10803-021-05030-8	This study evaluated HRQOL in 391 families of children diagnosed with one of the three genetic disorders that strongly predispose to syndromic autism: Phelan-McDermid syndrome, Rett syndrome, & SYNGAP1-related intellectual disability. Results found syndromic autism leads to worse QOL than other chronic disorders including idiopathic autism.
9	Braden, B. B., Pagni, B. A., Monahan, L., Walsh, M. J. M., Dixon, M. V., Delaney, S., Ballard, L., & Ware, J. E. (2022). Quality of life in adults with autism spectrum disorder: Influence of age, sex, and a controlled, randomized mindfulness-based stress reduction (MBSR) pilot intervention. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 31(5), 1427–1440. https://doi.org/10.1007/s11136-021-03013-x	This study investigated effects of sex & age on QOL of those with ASD and evaluated effectiveness of MBSR in improving their QOL using the 36-Item Short Form Survey to compare QOL in 67 adults with ASD and 66 neurotypical adults. Results showed that mental QOL is worse in both men & women with ASD, while older age is linked to better mental QOL of women. MBSR was also proven effective in improving QOL.
10	Burke, T., Deffew, A., Stafford, O., Docherty, C., Burke, S., Mostert, R., van Loon, J., Lombardi, M., Vaughan, M., Brickell, R., Keogh, M., Mahon, W., & O'Halloran, D. (2022). Quality of life outcomes in a community cohort of adults with an intellectual disability using the personal outcome scale. *Frontiers in Rehabilitation Sciences, 3*. https://doi.org/10.3389/fresc.2022.848492	This study examined QOL of those with ID, surveying 85 people using self-reported measures. Results showed QOL is higher in those with a service planner than those without a service planner.
11	Caron, V., Jeanneret, N., Giroux, M., Guerrero, L., Ouimet, M., Forgeot d'Arc, B., Soulières, I., & Courcy, I. (2022). Sociocultural context and autistics' quality of life: A comparison between Québec and France. *Autism*, *26*(4), 900-913. https://doi.org/10.1177%2F13623613211035229	This cross-sectional survey research study examined whether QOL determinants vary by country (or culture) by comparing two groups of French-speaking adults with ASD (n = 430) in France & Québec. Results demonstrated the importance of considering sociocultural context in measuring QOL of adults with ASD.
12	Cohen, S. R., Helbig, I., Kaufman, M. C., Myers, L. S., Conway, L., Helbig, K. L. (2022). Caregiver assessment of quality of life in individuals with genetic developmental and epileptic encephalopathies. *Developmental Medicine and Child Neurology*. https://doi.org/10.1111/dmcn.15187	This study evaluated QOL & its determinants, including disease severity, in individuals with developmental & epileptic encephalopathies (DEEs) through a tailored questionnaire. Results from ananlysis of 174 questionnaire responses

		indicated that QOL partially overlaps with objective measurements of disease severity & may stand for an independent outcome measure in precision medicine trials.
13	Correale, C., Borgi, M., Cirulli, F., Laghi, F., Trimarco, B., Ferraro, M., & Venerosi, A. (2022). The impact of health and social services on the quality of life in families of adults with autism spectrum disorder (ASD): A focus group study. *Brain Sciences*, 12(2), 177. https://doi.org/10.3390/brainsci12020177	This focus-group study aimed to understand how parents of adults with ASD view health services & how they impact QOL, with the goal of improving ASD intervention programs. Two focus groups of parents from 8 families were studied. Parents reported a lack of structured care & low integration levels as a limit of services, while reporting positive experiences as caring for families of those with ASD.
14	Darla, S., & Bhat, D. (2021). Health-related quality of life and coping strategies among families with Down syndrome children in South India. *Medical Journal Armed Forces India*, *77*(2), 187-193. https://doi.org/10.1016/j.mjafi.2020.07.010	This cross-sectional study with 51 parents of children with Down syndrome evaluated HRQOL & coping strategies. Results indicated that with increasing life expectancy, there is a gap between assessment of needs & providing medical aid for children with Down syndrome.
15	Davy, G., Unwin, K. L., Barbaro, J., & Dissanayake, C. (2022). Leisure, employment, community participation and quality of life in caregivers of autistic children: A scoping review. *Autism*, *26*(8), 1916-1930. https://doi.org/10.1177/13623613221105836	A review of 70 articles indicated that caregiving demands & challenges raising a child with autism often takes priority over the caregiver's own needs & desires, affecting occupational participation and QOL.
16	Dias, C., Schwertner, C., Grando, D., Bidinotto, A. B., Hilgert, J. B., Schuch, J. B., de Azeredo, L. A., Bauer, M. E., Hashizume, L. N. (2022). Caregiving of children with Down syndrome: Impact on quality of life, stress, mental and oral health. *Special Care in Dentistry, 42*(4):398-403. https://doi.org/10.1111/scd.12694	Participants included 54 caregivers of children with Down syndrome & 51 caregivers of children without disabilities. Down syndrome caregivers were older (48.6 vs. 41.5, $p < .001$), had longer caregiving periods (> 10 vs < 10 years, $p = .003$), had higher gingival bleeding index (6.1 vs. 4.7, $p = .014$) & cortisol levels (55.9 vs. 38.4, $p = .07$) than parents of children without disabilities. Sociodemographic data has no influence on cortisol levels ($p > .05$).
17	Dizdarevic, A., Memisevic, H., Osmanovic, A., Mujezinovic, A. (2022). Family quality of life: Perceptions of parents of children with developmental disabilities in Bosnia and Herzegovina. *International Journal of Developmental Disabilities*, *68*(3), 274-280. https://doi.org/10.1080%2F20473869.2020.1756114	This study examined how FQOL of 270 parents was associated with parental gender, age, employment status, and mental health (depression, anxiety, & stress); child's gender, age, & type of disability (mild & moderate ID, ASD). Results found that parents of children with ASD & parents of children with moderate ID had significantly lower FQOL than parents of children with mild ID & parents of typically developing children.
18	Evers, K., Maljaars, J., Schepens, H., Vanaken, G. J., & Noens, I. (2022). Conceptualization of quality of life in autistic individuals.	This study reviewed 174 articles, examining QOL in individuals with ASD. Results found parents reported a lower QOL compared with individuals

	Developmental Medicine & Child Neurology. https://doi.org/10.1111/dmcn.15205	with ASD themselves, especially on internal domains.
19	Günal, A., Pekçetin, S., Wagman, P., Håkansson C, Kayıhan H. (2022). Occupational balance and quality of life in mothers of children with cerebral palsy. *British Journal of Occupational Therapy*, *85*(1), 37-43. https://doi.org/10.1177/0308022621995112	This study examined differences in OB & QOL between mothers of children with CP & typically developing children with (n = 36) mothers of children with CP & (n = 36) mothers of typically developing children. Results found that the OBQ11-T, total score, & the item 'balance between obligatory & voluntary occupations' score differed significantly between the groups ($p < 0.05$).
20	Harriman, E., & Oyefeso, A. (2022). Defining quality of life for individuals with neurodevelopmental disorders: Challenges within an inpatient population. *Journal of Intellectual Disabilities*, 26(2), 455-469. https://doi.org/10.1177/1744629520982836	This study examined existing literature on QOL using specific inclusion & exclusion criteria. 30 articles were observed; results showed a need for further exploration of populations with neurodevelopmental disorders to address deinstitutionalization & community inclusion.
21	Herrera, E., Baena, S., Hidalgo, V., Trigo, E. (2022). The relationship between family quality of life, mindful attention, and social support in families of people with autism spectrum disorder. *International Journal of Developmental Disabilities,* 1-11. https://doi.org/10.1080/20473869.2022.2122248	This article indicated mindful attention (Mindful Attention & Awareness Scale: MAAS) of caregivers was a predictor of FQOL in 96 families of children with ASD after controlling for the family's social supports (Support Questionnaire for Parents with Children with Disability). Mindful attention interventions may help improve FQOL of families with children & adolescents with ASD.
22	Howe, S. J., Baraskewich, J., & McMorris, C. A. (2022). Anxiety in autistic youth: Understanding the impact on child, caregiver, and family quality of life. *Journal of Child and Family Studies*, 1-16. https://doi.org/10.1007/s10826-022-02277-2	Data gathered from 20 youth with ASD & anxiety & their caregivers gathered using the PedsQOL, PSI-4, Spanish FQOL scale Anxiety Disorders Interview Schedule – Autism Addendum: ADIS-ASA. Results showed higher levels of anxiety of youth with ASD was associated with lower child QOL influencing caregiver stress & FQOL.
23	Jansen-van Vuuren, J., Nuri, R. P., Nega, A., Batorowicz, B., Lysaght, R., & Aldersey, H. M. (2022). Family quality of life for families of children with disabilities in African contexts: A scoping review. *Quality of Life Research*, 1-19. https://doi.org/10.1007/s11136-021-02994-z	53 articles reviewed to ident factors contributing to FQOL. Poverty, stigma, & spirituality were prominent factors affecting FQOL negatively and positively in African contexts.
24	Kazda, L., McGeechan, K., Bell, K., Thomas, R., & Barratt, A. (2022). Association of attention-deficit/hyperactivity disorder diagnosis with adolescent quality of life. *JAMA Network Open, 5*(10), e2236364. https://doi.org/10.1001/jamanetworkopen.2022.36364	This study sampled 393 adolescents with ADHD using the Longitudinal Study of Australian Children, propensity score matching, & Child Health Utility 9D. Self-reported outcomes showed similar QOL among the participants, but worse psychological sense of school membership and self-efficacy.
25	Krauss, A., & Schellenberg, C. (2022). ADHD symptoms and health-related quality of life (HRQOL) of adolescents and young adults.	This cross-sectional study used a school-based sample to explore the connection between

	European Journal of Health Psychology, 29(4). https://doi.org/10.1027/2512-8442/a000104	ADHD & HRQOL of adolescents. A sample of 907 adolescents aged 14-24 years were surveyed. Results indicated a negative correlation between the two, & individuals reported lower self-esteem & lower physical & emotional health compared to peers.
26	Mason, D., Rodgers, J., Garland, D., Wilson, C., Parr, J. R., & McConachie, H. (2022). Measuring quality of life in autistic adults: The reliability and validity of the brief version of the world health organization quality of life scale (WHOQoL-BREF). *AMRC Open Research, 4*, 3. https://doi.org/10.12688/amrcopenres.13030.1	This study investigates the suitability of the WHOQoL-BREF as a tool to measure the QOL of autistic adults through a data analysis of 352 autistic adults aged 18-80 years. Four discussion groups were also formed. Results suggested that the WHOQoL-BREF is reliable.
27	Memisevic, H., Dordjevic, M., Glumbić, N. (2022). Quality of life for individuals with autism and pervasive developmental disabilities. In: Matson, J.L., Sturmey, P. (Eds). *Handbook of Autism and Pervasive Developmental Disorder.* Autism and Child Psychopathology Series. Springer, Cham. https://doi.org/10.1007/978-3-030-88538-0_7	The book chapter focused on QOL in ASD: Brief history of QOL & attempts to define it, description of different methods used for measurement, main constructs, & ideas on how to further enhance QOL in people with ASD.
28	Milićević, M. (2022). Functional and environmental predictors of health-related quality of life of school-age children with cerebral palsy: A cross-sectional study of caregiver perspectives. *Child: Care, Health and Development*. https://doi.org/10.1111/cch.13007	This study identified predictors of caregiver-reported HRQOL of 108 school-age children with CP using a cross-sectional survey. Results found home adaptation, supportive laws & policies & family-centered rehabilitation care that meets the family needs may promote children's HRQOL.
29	Milberger, S., Marsack., C., Janks E., Bray, M., Anderson, N., & Samuel., P.S (2022). Evaluating the benefits of a family support program on the health and well-being of aging family caregivers of adults with intellectual and developmental disabilities. *Journal of Gerontological Social Work, 11.* https://doi.org/10.1080/01634372.2022.2110347.	The study examined the benefits of MI-OCEAN using the FQOL framework. Quantitative analysis of data from 82 caregivers (>50 years) indicated that study participation improved caregiver outcomes (stress, depression, QOL and FQOL) and service use (e.g., Medicaid).
30	Movsessian, T., & Osoba, T. A. (2022). Association between therapeutic interventions and quality of life in people with autism. *Journal of Social, Behavioral, and Health Sciences,* 16(1). https://doi.org/10.5590/jsbhs.2022.16.1.21	This cross-sectional study examines the association of autism interventions with QOL of autistics adults. A survey on 182 adults with ASD to measure QOL, indicated that QOL was lower than the general population. Characteristics such as autism severity, being female, & older age negatively impacted QOL.
31	M. Saidul Islam, Sultana, A., Md. Zahid Hossain, & Jahan, S. (2022). Health-related quality of life of children with cerebral palsy among 3-12 years old. *European Journal of Medical and Health Sciences, 4*(5), 105–108. https://doi.org/10.24018/ejmed.2022.4.5.1388	This cross-sectional study examined QOL of 100 Bengali children with cerebral palsy. They had limited schooling & social integration, & lower QOL of children than their peers.
32	Øverland, E., Åshild Lappegard Hauge, Orm, S., Pellicano, E., Merete Glenne Øie, Erik Winther Skogli, & Andersen, P. (2022). Exploring life with autism: Quality of life, daily functioning and compensatory strategies from childhood to emerging adulthood: A qualitative study protocol. *Frontiers in Psychiatry, 13*. https://doi.org/10.3389/fpsyt.2022.1058601	This study will investigate self-perceived QOL, daily functioning, & use of compensatory strategies of emerging adults with autism living in Norway from Lillehammer Neurodevelopmental 10-year follow-up study (LINEUP). Methods will include 15 in-depth

		interviews with adults and 2 focus groups with clinicians.
33	Randell, E., Wright, M., Milosevic, S., Gillespie, D., Brookes-Howell, L., Busse-Morris, M., ... & McNamara, R. (2022). Sensory integration therapy for children with autism and sensory processing difficulties: the SenITA RCT. *Health Technology Assessment*, *26*(29). https://doi.org/10.3310/TQGE0020	Parallel-group RCT to evaluate efficacy of a manualized sensory integration therapy delivered to 138 participants (68 per group) over 26 weeks (comparator was usual care) in Wales, England. Study outcomes included problem behaviors (Aberrant Behavior Checklist); Adaptive behaviour (Vineland Adaptive Behavior Scales); carer stress (Autism Parenting Stress Index); QOL (EuroQol-5 Dimensions and Carer Quality of Life); functional change (Canadian Occupational Performance Measure); Sensory Processing Measure; and cost-effectiveness (Client Service Receipt Inventory). Intervention did not demonstrate clinical/economic benefit above standard care; intervention is likely to be effective for individualized performance goals.
34	Schmidt, S., Markwart, H., Rapp, M., et al. (2022). Quality of life and mental health in emerging adults with cerebral palsy compared to the general population. *Health and Quality of Life Outcomes*, *20*(1), 1-13. https://doi.org/10.1186/s12955-022-01961-7	This study compared 198 adults having CP with 593 neurotypical emerging adults using QoL (WHOQOL-BREF), depression (PHQ-9), anxiety (GAD-7) & self-efficacy (GSE). Results found similar outcomes in both groups to indicate that emerging adults with CP have high adaptive capabilities.
35	Sonido, M. T., Hwang, Y. I., Srasuebkul, P., Trollor, J. N., Arnold, S. R. C. (2022). Predictors of the quality of life of informal carers of adults on the autism spectrum. *Journal of Autism and Developmental Disorders*, *52*(7), 2997-3014. https://doi.org/10.1007/s10803-021-05178-3	This study explores Sonido et al. (2019) conceptual model using the psychological domain of the World Health Organization Quality of Life-BREF (WHOQOL) as the outcome measure. Analysis of 101 carer questionnaires were reviewed to identify predictors associated with carer psychological QOL, including carer age, care recipient ID, & carer intolerance of uncertainty and the study recommends tailored interventions for carers of autistic adults.
36	Widyawati, Y., Scholte, R. H. J., Kleemans, T., Scholte, R. H. J. (2022). Parental resilience and quality of life in children with developmental disabilities in Indonesia: The role of protective factors. *Journal of Developmental and Physical Disabilities*, 1-16. https://doi.org/10.1080/1034912X.2020.1834078	Study examined associations between different dimensions of parental resilience & QOL of children in Indonesia with a sample of 497 families. Results found parental resilience is related to QOL of children with DDs.
37	Wang, F., Marsack-Topolewski, C. N., DiZazzo-Miller, R., Samuel, P. (2022). Health of aging families: Comparing compound and noncompound caregivers. *Journal of Gerontological Social Work, 65*(3), 290-304. https://doi.org/10.1080/01634372.2021.1963024	The study used web-based cross-sectional survey data from 112 aging caregivers. Results found compound caregivers had poorer perceptions of personal health than noncompound caregivers. Compound caregivers had lower health attainment & satisfaction with family health than noncompound caregivers.
38	Weir, E., Allison, C., & Baron-Cohen, S. (2022). Autistic adults have poorer quality healthcare and worse health based on self-report data. *Molecular Autism*, 13(1). https://doi.org/10.1186/s13229-022-00501-w	This Cross-sectional analysis of online survey conducted from 2649 participants (1285 individuals with autism) reports a significant difference in health care quality between those

with and without autistic features, particularly relating to the aspect of communication and anxiety from the self-reported survey.

	2023	**Summary of Work**
1	Amor, A. M., Verdugo, M., Fernández, M., Aza, A., Sánchez-Gómez, V., & Wolowiec, Z. (2023). Development and validation of standardized quality of life measures for persons with IDD. *Behavioral Sciences*, *13*(6), 452. https://doi.org/10.3390/bs13060452	Explores (a) need to identify critical population groups & contexts; (b) identification of QoL indicators for groups and contexts; (c) development of items focused on the assessment of personal outcomes; (d) provision to the items of validity evidence based on content and pilot measure design and (e) validation process to gather evidence that supports the uses of the instrument. Last, a framework that allows using the evidence on personal outcomes as disaggregated and aggregated data at different levels of the social system is presented, thus highlighting the role of the model as a change agent regarding individuals, organizations and schools, and public policy.
2	Bamber, M. D., Mahony, H., & Spratling, R. (2023). Mothers of children with special health care needs (CSHCN): Exploring caregiver burden, quality of life, and resiliency. *Journal of Pediatric Health Care*, *37*(6), 643–651. https://doi.org/10.1016/j.pedhc.2023.06.003	This cross-sectional survey of 106 mothers of CSHCN examined caregiver burden, QOL, and resilience in mothers of CSHCN. Mothers of CSHCN showed higher burden and lower QOL.
3	Boland, G., & Guerin, S. (2023). Supporting social inclusion in neighbourhoods of adults with intellectual disabilities: service providers' practice experiences. *Journal of Intellectual Disabilities, 27*(2), 291-314. https://doi.org/10.1177/17446295221085479	This national survey of CEOs/service leaders gives an in-depth account of service providers' practice initiatives supporting the social inclusion in neighbourhoods of adults with intellectual disabilities. Results reveal a complex service context, and leaders report facilitators, alongside many challenges that may impede progress on social inclusion.
4	Boland, G., de Paor, E., & Guerin, S. (2023). Living in localities: the factors that influence the social inclusion in neighborhoods of adults with intellectual disability. A systematic scoping review. *Inclusion*, *11*(1), 55-77. https://doi.org/10.1352/2326-6988-11.1.55	This systematic scoping review examined research on social inclusion in neighborhoods for adults with intellectual disabilities, synthesizing 94 peer-reviewed studies published between 2000 and 2020. The characteristics of neighborhoods that foster inclusion are identified, alongside a range of other factors that influence this important quality of life domain.
5	Brennan, D., D'Eath, M., McCallion, P., & McCarron, M. (2023). Health and Well-being of sibling carers of adults with an intellectual disability in Ireland: Four waves of data. *British Journal of Learning Disabilities*, *51*(4), 534–543. https://doi.org/10.1111/bld.12532	This survey of 218 family caregivers examines the health and well-being of family caregivers of older adults with ID in Ireland. The results showed that caregiving takes a physical, mental, and financial toll on caregivers.
6	Bruinsma, E., van den Hoofdakker, B. J., Hoekstra, P. J., de Kuijper, G. M., & de Bildt, A. A. (2023). Effects of positive behaviour support [PBS] delivered by direct staff on challenging behaviours and quality of life of adults with intellectual disabilities: A Multicentre cluster-	This study used 26 teams of residential group homes: 245 staff members & 167 individuals with IDs, to understand effects of staff provided PBS for individuals with IDs compared to controls. PBS reduced irritability of individuals

	controlled trial. *Journal of Applied Research in Intellectual Disabilities*, *37*(1). https://doi.org/10.1111/jar.13164	with IDs, decreased lethargic behaviors, and improved personal development and self-determination.
7	Cardoso, A. L., Silva-Junior, G. O., Bastos, L. F., Cesar, A. L., Serrano, L. G., Dziedzic, A., & Picciani, B. L. (2023). Preliminary assessment of the quality of life and daily burden of caregivers of persons with special needs: A questionnaire-based, cross-sectional survey. *International Journal of Environmental Research and Public Health*, *20*(3), 1–11. https://doi.org/10.3390/ijerph20032012	This survey of 60 caregivers of individuals with special needs examined QOL and daily workload of informal caregivers. Caregiving caused moderate overload which decreased QOL.
8	Çınar, H. Ü., Kızılkan, M. P., Akalın, A., Kiper, P. Ö., Utine, G. E., Derman, O., Kanbur, N., & Akgül, S. (2023). Assessing the menstrual cycle and related problems in adolescents with a genetic syndrome associated with intellectual disability. *Journal of Pediatric and Adolescent Gynecology*. https://doi.org/10.1016/j.jpag.2023.02.005	The aim of this prospective cross-sectional study was to assess QoL related to menstruation in 49 adolescents with a genetic syndrome accompanying ID. Findings showed QOL decrease, increased school absenteeism, and a high percentage of needing assistance while menstruating.
9	Çolak, B., & Kahriman, I. (2023). Evaluation of family burden and quality of life of parents with children with disability. *The American Journal of Family Therapy*, *51*(2), 113-133. http://dx.doi.org/10.1080/01926187.2021.1941421	This research was conducted to determine the family burden and QOL of 518 parents of children with disabilities using Family Burden Assessment Scale (FBAS), WHO QOL Scale Short Form Turkish Version, Parents educational level affected family burden and QOL and the family burden of the mothers was found to be higher than fathers and their QOL was lower.
10	Da Costa, I. G., Brugnaro, B. H., Lima, C. R., Kraus de Camargo, O., Fumincelli, L., Pavão, S. L., & Rocha, N. A. (2023). Perceived social support (PSS) and quality of life of children with and without developmental disabilities and their caregivers during the COVID-19 pandemic in Brazil: A cross-sectional study. *International Journal of Environmental Research and Public Health*, *20*(5), 1–14. https://doi.org/10.3390/ijerph20054449	This survey of 89 caregivers compared the role of perceived social support and QOL in caregivers of children with and without DD. While there were no differences in PSS, caregivers of children with DD had lower QOL.
11	Emerson, E., Totsika, V., Hatton, C., & Hastings, R. P. (2023). The mental health and well-being of adolescents with/without intellectual disability in the UK. *Epidemiology and Psychiatric Sciences*, *32*, 1–9. https://doi.org/10.1017/s204579602300080x	Participants comprised 10,838 14-year-olds (361 had ID) & 9,408 17-year-olds (292 had ID) and their parents who completed multiple questionnaires about adolescents' mental health and well-being Strengths and Difficulties Questionnaire, Short-Form Moods and Feelings Questionnaire, Kessler (K6) questionnaire, Short Warwick-Edinburgh Mental Well-Being Scale, Short Rosenberg Self-Esteem Questionnaire).. Parental reports highlighted increased likelihood of problems for children with ID, at both ages, having problems. Self-reported data from the 17-year-olds showed that those with ID had a lighter likelihood of problems in almost all SDQ domains. There were no group differences in

		either age group with or without ID for the rest of the questionnaires.
12	Francisco, C., Ibáñez, A. y Balcells-Balcells, A. (2023). Participants' bias in disability research on Family Quality of Life during the 0-6 years stage" en *Revista Behavioral Sciences*. https://doi.org/10.3390/bs13090753	The findings indicate that most studies examining the FQOL were based on the information of a single informant per family unit. The profiles of participants according to the research objective are quite similar. In one-third of studies, the authors reported that family members who participate cannot be represented by only mothers or one participant per household.
13	Franco, E., Ocete, C., Pérez-Calzado, E., & Berástegui, A. (2023). Physical activity and quality of life among people with intellectual disabilities: The role of gender and the practice characteristics. *Behavioral Sciences*, *13*(9), 773. https://doi.org/10.3390/bs13090773	The study examines influence of gender in physical sport activity, association with physical activity vs. QOL & QOL vs non-regulated/sports-based practice activity in 380 PWID from the self/proxy completed questionnaires and states no association between the gender and physical sport activity practice or type & the participants in non-regulated activity had higher scores in QoL personal dimensions (self-determination/personal development) & sport activity group scored higher in interpersonal relationships & physical well-being.
14	Gutiérrez-Cruz, C., Muñoz-López, S., Rubio-Cabeza, J., Raya-Castellano, P. E., & Roman-Espinaco, A. (2023). Employability Skills, quality of life, and body composition on employment modalities in individuals with mild and moderate intellectual disabilities. *Journal of Intellectual Disabilities*, 174462952311681. https://doi.org/10.1177/17446295231168176	125 users belonging to 3 employment modalities of Occupational Workshops (OW), Occupational Centers (OC) and Supported Employment (SE), participated in this study. Differences between modalities were determined for employability, quality of life, and body composition. Employability skills were higher for SE compared to OW and OC; the index of quality of life was higher for OC and SE groups compared to OW; no differences were found in body composition between groups.
15	Ijezie, O. A., Healy, J., Davies, P., Balaguer-Ballester, E., & Heaslip, V. (2023). Quality of life in adults with Down Syndrome: A mixed methods systematic review. *PLOS ONE*, *18*(5). https://doi.org/10.1371/journal.pone.0280014	Using Schalock and Verdugo's multidimensional quality of life assessment model, this systematic review aimed to identify, synthesize and integrate quantitative and qualitative evidence on QOL in adults with Down syndrome via self- and proxy-reporting.
16	Jacinto, M., Rodrigues, F., Monteiro, D., Antunes, R., Ferreira, J. P., Matos, R., & Campos, M. J. (2023). Quality of life in individuals with intellectual and developmental disabilities: The congruency effect between reports. *Healthcare*, *11*(12), 1748. https://doi.org/10.3390/healthcare11121748	Assessed congruence between QOL perceptions of institutionalized individuals with IDD and third-party. Portuguese version of Personal Outcomes Scale used with 42 individuals (including 21 with mild to severe IDD and their families). Significant differences found between

		reports in personal development, emotional well-being, physical well-being and total QoL indicate that most third-party reports undervalue QoL of individuals with IDD.
17	Jacob, U. S., Pillay, J., Johnson, E., Omoya, O., & Adedokun, A. P. (2023). A systematic review of physical activity: Benefits and needs for maintenance of quality of life among adults with intellectual disability. *Frontiers in Sports and Active Living*, *5*, 1184946. https://doi.org/10.3389/fspor.2023.1184946	This study reviewed 15 papers on benefits of physical activity: benefits and needs for maintenance of QOL among adults with ID. Results indicate that physical activity has a moderate to strong positive impact on weight loss, sedentary behavior, & QOL.
18	Karni-Visel, Y., Nasser, K., Manishevitch, H., Akrt, S., & Schertz, M., (2023). Family quality of life in children with severe or profound disability: Home versus residential care. *Journal of Developmental & Behavioral Pediatrics, 44*(1), e32-e40. https://doi.org/10.1097/DBP.0000000000001138	The study compared FQOL among 60 families raising children (2-18 yrs) with severe and profound ID at home versus in residential care. FQOL was higher and parental stress lower among families of children in residential care, highlighting the need for targeted support for families raising children with SPID at home.
19	Laufenberg, H., Ausderau, K., Caudill, A., & Hickey, E. (2023). Impacts of the COVID-19 pandemic: Quality of Life & Access to health care among individuals with Intellectual & Developmental Disabilities. *The American Journal of Occupational Therapy*, *77*(Supplement_2). https://doi.org/10.5014/ajot.2023.77s2-po239	This research poster examined pre- and mid-pandemic access to health care and QOL among adults with IDD. Identification of barriers faced by adults with IDD allows practitioners to better address their needs by tailoring interventions and supports. Comparison of pre- (2017) and mid-pandemic (2021) access to specialized healthcare and QoL among adults with IDD receiving long term care support services indicated that QOL was higher in the 2017 cohort.
20	Ling, G., Potměšilová, P., & Potměšil, M. (2022). Families who have a child with a disability: A literature review of quality of life issues from a Chinese perspective. *Journal of Family Social Work*, *25*(2–3), 67–87. https://doi.org/10.1080/10522158.2023.2165586	Literature review characterized & analyzed available QOL research in families with a child with a disability in China. This review consolidates the empirical research to date on FQOL & outlines areas of research for further exploration.
21	Ljungberg, M., & Schön, U. (2023). Who cares? A scoping review about the experiences of parental caregivers of autistic adults. *Journal of Applied Research in Intellectual Disabilities*, *36*(5), 929–939. https://doi.org/10.1111/jar.13126	This scoping review maps, synthesizes and identifies gaps in previous research as regards the experiences of parental caregivers of adult autistic children. Their view was based on Arksey and Malley's framework, & 6 databases were searched. Two studies reported that access to informal support partially mediated the relationship between the caregiver burden and QOL.
22	Maguire, S., Davison, J., McLaughlin, M., Simms, V., & Bunting, B. (2023). Exploring the psychometric properties of self-report instruments used to measure health-related quality of life and subjective wellbeing of adolescents with intellectual disabilities: A	This review critically appraised evidence on psychometrics of self-report instruments that measure HRQoL and subjective wellbeing of adolescents with ID. COSMIN used to evaluate

	consensus-based standards for the selection of Health Measurement Instruments (COSMIN) systematic review. *Journal of Applied Research in Intellectual Disabilities*, *36*(5), 899–915. https://doi.org/10.1111/jar.13110	evidence from 7 studies that met the inclusion criteria out of 5134 studies. PSI-VS-ID, ID version of short form of physical self-inventory demonstrated good internal consistency, structural validity, construct validity, cross-cultural and criterion validity and is recommended by the authors to be used with caution since it requires further validation due to small sample size. Four instruments (WELLSEQ, CHEQOL -25, AUQUEI, CAPE) had insufficient measurements and were not recommended.
23	Marsack-Topolewski, C. N. (2023a). Fathers of adult children with autism: Examination of caregiver burden, social support, and quality of life. *Journal of Child and Family Studies*. https://doi.org/10.1007/s10826-023-02673-2	This study examined the influence of caregiver burden, perceived informal social support, and number of formal social supports on QOL of 57 fathers of adults with ASD. Multiple linear regression analysis indicated developmental burden was negatively related to QOL, with informal social support positively related to QOL.
24	Marsack-Topolewski, C. N. (2023b). Predictors of quality of life for aging family caregivers of adults with autism. *Journal of Family Social Work*, *25*(2–3), 109–125. https://doi.org/10.1080/10522158.2023.2165584	This study determined if domains of caregiver burden & informal social support were predictors of QOL for 320 aging parental caregivers (50 +) of adults with ASD (18+). Multiple linear regression analysis indicated that developmental burden, emotional burden, and informal social support predicted QOL after controlling caregiver age and self-reported health.
25	Marsack-Topolewski, C., Milberger, S., Janks, E., Anderson, N., Bray, M., & Samuel, P. S. (2023). Evaluation of peer-mediated systems navigation for ageing families of individuals with developmental disabilities. *Journal of Intellectual Disability Research*, *67*(5), 462-474. https://doi.org/10.1111/jir.13024	This study evaluated a state-wide support project designed to help 82 ageing caregivers of adults with IDD access services. Participants reported fewer barriers in service access and increased use of formal services, which demonstrates the project's effectiveness in providing support to caregivers through peer mentors.
26	Mbatha, N. L., & Mokwena, K. E. (2023). Parental stress in raising a child with developmental disabilities in a rural community in South Africa. *International Journal of Environmental Research and Public Health*, *20*(5), 1–15. https://doi.org/10.3390/ijerph20053969	This cross-sectional survey of 335 female caregivers quantified parental stress in female caregivers of children with DD. The results showed a high level of parental stress found.
27	Milberger, S., Marsack-Topolewski, C., Janks, E., Anderson, N., Bray, M., & Samuel, P. S. (2023). Evaluating the Benefits of a Family Support Program on the Health and Well-Being of Aging Family Caregivers of Adults with Intellectual and Developmental Disabilities. *Journal of Gerontological Social Work*, *66*(3), 413–432. https://doi.org/10.1080/01634372.2022.2110347	This article examines the benefits of a family support program on the health and well-being of aging caregivers for adults with intellectual and developmental disabilities (IDD). The study analyzed the experiences of caregivers and found improvements in their emotional health, reduced stress, and better access to formal support services. The results highlight the

		importance of structured support programs in improving caregiver quality of life, with key implications for service providers and policymakers focused on aging populations.
28	Morán, L., Gómez, L. E., Verdugo, M. Á., & Schalock, R. L. (2023). The quality of life supports model as a vehicle for implementing rights. *Behavioral Sciences*, *13*(5), 365. https://doi.org/10.3390/bs13050365	The aim of this conceptual paper is twofold. Firstly, it aims to show the overlap between the QOLSM and the Convention on the Rights of People with Disabilities (CRPD), highlighting how the former can be used to address many of the goals and rights embedded in the latter. Secondly, the article seeks to illustrate the connection between these two frameworks and highlight the importance of acknowledging and measuring the rights of people with IDD.
29	Mumbardó-Adam, C., Vicente, E., & Balboni, G. (2023). Self determination and quality of life of people with intellectual and developmental disabilities: Past, present, and future of Close Research Paths. *Journal of Policy and Practice in Intellectual Disabilities*. https://doi.org/10.1111/jppi.12460	To understand how self-determination is an essential supporting concept in the QOL paradigm, this brief report unravels the complementary but unique role that each construct (QOL and self-determination) embodies. Furthermore, we discuss the role of self-determination in scientific literature and in the quality of life of people with intellectual and DD, reflecting on how both lines of research can converge and be aligned from a common approach. The aim is to drive attention to areas of future research development that strengthen understanding of quality of life and the self-determination construct.
30	Mumbardó-Adam, C., Vicente, E., Simó-Pinatella, D., & Balboni, G. (2023). Understanding how self-determination affects the quality of life of young people with intellectual disability. *International Journal of Disability, Development and Education*, 1–19. https://doi.org/10.1080/1034912x.2023.2212619	This study explores the impact of personal characteristics (age, gender, intellectual disability level), and diagnosis of ASD and the context-related variable of self-determination on QoL, in 100 adolescents with intellectual disability in a single school. The Kids Life scale of QoL and the AUTODDIS scale of self-determination were used, with the participants' teachers acting as respondents. QOL was influenced by self-determination in the domains of personal development, well-being and social inclusion.
31	Muñoz-López, S., Molina-Garcia, P., Gutiérrez-Cruz, C., Ubago-Díaz, R., Romero-Ayuso, D., & Ariza-Vega, P. (2023). The influence of meaningful activities in the quality of life and functional autonomy of adults with intellectual disability: A prospective study during the COVID-19 pandemic. *Journal of Applied Research in Intellectual Disabilities*, *36*(3), 538-546. https://doi.org/10.1111/jar.13077	The study analyzed the changes in QOL, functional autonomy & functional independence in 73 people with ID in residential homes during COVID-19 pandemic (Nov 2019, Jan 2020, Apr-Sep2020) using GENCAT, FIM, & the Lawton Instrumental ADL scales. The pandemic had a negative impact on QoL and functional autonomy in PWID. Prior to COVID-19, community self-management activities were

		associated with less detriment to QoL, and higher number of occupational and physical activities were associated with less detriment to the functional autonomy.
32	Múries-Cantán, O., Giné, C., Brown, R. I., Aguiar, N. B., & Schippers, A. P. (2023). Siblings of children with intellectual and developmental disabilities: Quality of life perceptions from Catalonia. *Journal of Policy and Practice in Intellectual Disabilities*, *20*(2), 192–204. https://doi.org/10.1111/jppi.12451	Siblings' interactions and shared experiences influence their perceptions of quality of life. The main aim was to collect siblings' perceptions on quality of life from siblings' own voices. Semi-structured interviews were conducted with 14 siblings aged 5–11 years old and thematically analyzed using the following domains: joint activities; mutual understanding; private time; acceptance; forbearance; trust in well-being; exchanging experiences; social support; and dealing with the outside world.
33	Northrup, R. A., Jones, E., Singh, V., Holingue, C., Meck, M., Gurnett, C. A., van Stone, M., & Kalb, L. G. (2023). Caregiver perspectives on the continued impact of the COVID-19 pandemic on children with intellectual/developmental disabilities. *Frontiers in Pediatrics*, *11*, 1–8. https://doi.org/10.3389/fped.2023.1196275	This survey of 249 caregivers examined the long-term impact of COVID-19 on children with IDD. Results showed that caregivers displayed significant negative effects (e.g., depression, social support, etc.).
34	Özkan, Z., & Kale, R. (2023). Investigation of the effects of physical education activities on motor skills and quality of life in children with intellectual disability. *International Journal of Developmental Disabilities*, *69*(4), 578-592. https://doi.org/10.1080/20473869.2021.1978267	This study compares the effects of a 14-week physical education activity program on the motor skills and QOL, study participants (age 8-12 yrs, experimental = 18, control =16) were evaluated using Bruininks Oseretsky test of motor proficiency second edition brief form & parent form of the "Pediatric Quality of Life Inventory (PedsQL) scale" and the experimental group showed statistically significant improvement in the post test score compared to the control group.
35	Papadopoulos, D. (2023). Impact of child and family factors on caregivers' mental health and psychological distress during the COVID-19 pandemic in Greece. *Children*, *11*(1), 1–15. https://doi.org/10.3390/children11010007	This survey study of 156 caregivers examined the mental health of caregivers of children with and without DD in Greece during COVID-19. Caregivers of children with DD had more mental health problems and higher levels of psychological distress.
36	Randall, K. N., Bernard, G., & Durah, L. (2023). Association between employment status and quality of life for individuals with intellectual or developmental disability. *Journal of Applied Research in Intellectual Disabilities*, *36*(2), 270-280. https://doi.org/10.1111/jar.13053	This study used the Comprehensive QOL Scale Intellectual/Cognitive Disability (objective QoL) and Personal Wellbeing Index - Intellectual Disability (subjective QoL) in relation to type of employment (competitive employment n = 8, work center n =14, or unemployment n = 5) in 27 adults (*M* = 45 years) with ID. Those in competitive jobs had higher scores in objective QOL than individuals in other employment,

		although they were not as satisfied with the work environment. Subjective scores were similar across all groups.
37	Romaniuk, A. (Ed.). (2023). *Predicting family quality of life in parents of children with elevated symptoms of attention-deficit/hyperactivity disorder.* University of Manitoba. https://mspace.lib.umanitoba.ca/items/408b242b-9ecb-4a98-89b3-eb7970bdb6e1	This thesis studied 145 parents (105 mothers & 40 fathers) of children aged 5 to 12 years, with elevated symptoms of ADHD from Canada and USA completed an online survey. The FQOL of coupled 13 parents were examined to understand the relationship between FQOL and parenting stress in mothers and fathers, and which child and parental factors predict FQOL. FQOL and parenting stress were negatively correlated for both parents, however, only significant for mothers. Parental social support was the strongest predictor of FQOL for both mothers and fathers.
38	Rosenberg, E. K. K. (2023, August). *An Investigation of the Quality of Life of Caregivers of Children with Disabilities*. Proquest. https://doi.org/doi:10.7282/t3-sckr-vk50	This thesis describes a quantitative study of 258 caregivers of children with disabilities, QOL was investigated in relation to a child's disability type & level of externalizing behavior. A factorial ANOVA was used to examine the main effects of child disability type & externalizing behavior on parent/caregiver QOL.
39	Rozensztrauch, A., Wieczorek, K., Twardak, I., & Śmigiel, R. (2023). Health-related quality of life and family functioning of primary caregivers of children with Down syndrome. *Frontiers in Psychiatry*, *14*, 1–9. https://doi.org/10.3389/fpsyt.2023.1267583	This survey study on 52 parents of children with Trisomy 21 examined the QOL of children with Trisomy 21 and the family impact. Trisomy 21 had a significant impact on lowering QOL and there was a positive correlation between the children's QOL, parents QOL, and overall family function.
40	Samuel, P.S. (2023). Family quality of life application among aging caregivers of adults with intellectual/developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 21*(1), e12475. https://doi.org/10.1111/jppi.12475	Discusses the application of international FQOL framework for aging caregivers of adults with IDD. It describes unique challenges these caregivers face and evaluates the effectiveness peer support to navigate systems using peer support to improve their FQOL.
41	Sharp, R. A., Phillips, K. J., & Taylor, S. A. (2023). People with intellectual and developmental disabilities. *Handbook of Applied Behavior Analysis*, 1277–1303. https://doi.org/10.1007/978-3-031-19964-6_66	Discusses how the current behavioral literature allows clinicians and researchers to conduct work that aligns with the 2006 *UN Convention on the Rights of Persons with Disabilities*. Despite significant improvements in behavior-analytic programs for people with IDD, there remains room for improvement regarding ensuring people with IDD have access to the full range of life experiences.

42	Singer, H., Clarke, E., Schiltz, H., & Lord, C. (2023). Caregivers and coping: Well-being (WB) and coping styles among caregivers of young adults (YA) with developmental disabilities. *MedRxiv*, 1–31. https://doi.org/10.1101/2023.02.24.23286429	This survey research of 134 caregivers of YA with DD examined caregiver WB and predictors of WB. Low caregiver education and high externalizing characteristics of the YA negatively impacted caregiver WB and coping styles can predict long term caregiver WB.
43	Singh, N. N., Lancioni, G. E., Hwang, Y.-S., Myers, R. E., Townshend, K., & Medvedev, O. N. (2023). Using mindfulness to improve quality of life in caregivers of individuals with intellectual disabilities and autism spectrum disorder: Agency outcomes for caregivers and clients. *Advances in Neurodevelopmental Disorders*, *7*(4), 604–615. https://doi.org/10.1007/s41252-023-00353-2	This survey research study on 216 caregivers examined changes in QOL related to caregivers and clients in community-based group homes. Mindfulness training yielded the best results for caregivers' QOL.
44	Staunton, E., Kehoe, C., & Sharkey, L. (2023). Families under pressure: Stress and quality of life in parents of children with an intellectual disability. *Irish Journal of Psychological Medicine, 40(2),* 192–199. https://doi.org/10.1017/ipm.2020.4	This article examined the relationship between stress and QOL in 33 parents of children with ID and described the significant pressures faced by these parents (emotional, financial, and social challenges) that negatively impact their well-being. The tools used were Aberrant Behaviour Checklist (ABC), Parenting Stress Index (PSI), Family Quality of Life Scale (FQOL), modified Family Support Scale (M-FSS) and Children's Global Assessment Scale (CGAS).
45	Syriopoulou-Delli, C. K. (2023). Quality of life in people with intellectual and developmental disability, autism: Advances in practice and Research. *International Journal of Developmental Disabilities*, *69*(3), 359–361. https://doi.org/10.1080/20473869.2023.2205287	This special issue features several articles addressing the importance of improving QoL for individuals with IDD and their caregivers. The issue showcases some of the recent advances in both practice and research aimed at enhancing QoL for this population.
46	Tefera, A. T., Girma, B., Adane, A., Muche, A., Ayele, T. A., Getahun, K. A., Aniley, Z., Ali, S., & Handebo, S. (2023). Oral health-related quality of life [OHRQOL] and oral hygiene status among special need school students in Amhara Region, Ethiopia. *Health and Quality of Life Outcomes*, *21*, 1–11. https://doi.org/10.1186/s12955-023-02110-4 https://doi.or	The study described the relationship between OHRQOL and oral hygiene status in 443 students at a special needs school in Ethiopia. OHRQOL was assessed from 14 questions (0-5 ordinal scale) about functional limitations, physical pain, psychological discomfort, physical disability, psychological disability, social disability, and handicap. Students had poor oral hygiene and there was a strong positive correlation between the factors included in the oral health impact profile, except for functional limitations and psychological discomfort.
47	Vinoski Thomas, E., Schram, B. M., Bari, S., Odunlami, R., Ormond, K. M., & Smith, S. E. (2023). Health and quality of life among people with intellectual and developmental disabilities and direct support professionals during the early United States COVID-19 pandemic. *Developmental Disabilities Network Journal, 3*(2), Article 3. https://doi.org/10.59620/2694-1104.1047	The purpose of this article is to understand how COVID 19 has influenced QoL and overall well-being among these populations. A rapid qualitative inquiry study with 18 people with IDD and their DSPs indicated that QOL changes were typically negative and influenced primarily by reduced socialization & impacts on health and independence.

48	Tsang, W., Oliver, D., & Triantafyllopoulou, P. (2023). Quality of life measurement tools for people with dementia and intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, *36*(1), 28–38. https://doi.org/10.1111/jar.13050	The aims of this systematic review are to (a) identify whether there are QoL measures available for people with dementia within the ID population and compare the psychometric properties and appropriateness of the measures, (b) to assess the scope & domains included in the QoL measures, theoretical and conceptual frameworks, and the extent of user or patient involvement in their development, by type of user, and (c) to suggest research implications and recommendations.
49	Verdugo, M. Á., Schalock, R. L., & Gómez, L. E. (2023). The quality of life supports model as a major component in applying the quality of life paradigm. *Journal of Policy and Practice in Intellectual Disabilities*. https://doi.org/10.1111/jppi.12468	The article describes (a) 4 elements of the QOLSM (core values, individual and family QOL domains, systems of support, and facilitating conditions); (b) use of the QOLSM in the field of IDD as a framework for supports provision. The article also discusses how QOLSM represents a value-based & action able model that should be effective for solving problems regarding services and supports to people with IDD, developing new knowledge, making meaningful change, being evaluated, & contributing theoretically and operationally to the field.
50	Vukićević, A., Švraka, E., Mačak Hadžiomerović, A., & Salkić, N. (2023). Quality of life of families with children with intellectual and developmental disabilities: Family health domain. *Journal of Health Sciences*, *13*(2), 91–97. https://doi.org/10.17532/jhsci.2023.2104	This survey of 110 families examined the difference in QOL between families with and without children with IDD for family health. Families with children with IDD had lower QOL for family health.
51	Wormald, A., McGlinchey, E., D'Eath, M., Leroi, I., Lawlor, B., McCallion, P., McCarron, M., O'Sullivan, R., & Chen, Y. (2023). Impact of covid-19 pandemic on caregivers of people with an intellectual disability, in comparison to carers of those with other disabilities and with Mental Health Issues: A multicountry study. *International Journal of Environmental Research and Public Health*, *20*, 1–14. https://doi.org/10.3390/ijerph20043256	The purpose of the survey research study was to understand the impact of COVID-19 on 3930 caregivers of people with ID (491: mental health difficulties; 1888 cared for people with dementia, 1147: physical disabilities, 404: ID) compared to other disabilities and mental health issues. It was found that 65% of caregivers of people with ID had increased burden and 35% of caregivers of people with ID and another condition experienced more severe loneliness.
52	Yadav, G. K., Vidales, B. M., Rashwan, H. A., Oliver, J., Puig, D., Nandi, G. C., & Abdel-Nasser, M. (2023). Effective ML-based quality of life prediction approach for dependent people in guardianship entities. *Alexandria Engineering Journal*, *65*, 909–919. https://doi.org/10.1016/j.aej.2022.10.028	This paper proposes an effective approach for predicting QoL for dependent individuals in guardianship entities. In addition, it aims to improve the QoL of people with intellectual disabilities. The proposed QoL prediction approach employs machine learning (ML) techniques to model the relationship between eight aspects of QoL and the corresponding QoL index.

53	Zaidman-Zait, A., Curle, D., & Jamieson, J. R. (2023). Health-related quality of life among mothers of children with cochlear implants (CI) with and without developmental disabilities (DD). *Research in Developmental Disabilities*, *133*, 104397. https://doi.org/10.1016/j.ridd.2022.104397	This study examined the relationship between functioning of 100 children with CIs (54 in CI with DD group), their mothers' coping resources (i.e., social support and family-centered care), and maternal HRQoL. Mothers of deaf children with CIs and DD experienced lower levels of family functioning and HRQoL across all dimensions compared to mothers of deaf children with CIs without DD. Social support was positively related to HRQoL only among mothers of children in the CI-DD group, indicating the protective role of social support.

	2024	**Summary of Work**
1.	Alnahdi, G. (2024). Enhancing the quality of life of mothers of children with intellectual disabilities or Autism: The role of disability-specific support. *Research in Developmental Disabilities, 151*, 104780. https://doi.org/10.1016/j.ridd.2024.104780	This article highlights the unique challenges of 269 Saudi Arabian families with children who have been diagnosed with intellectual disabilities or autism. Specialized interventions can reduce stress, enhance coping strategies, and contribute to a better quality of life. The study emphasizes the importance of targeted support systems in fostering resilience and improving the overall mental health of these caregivers.
2.	Alnahdi, G. H. (2024). Variations in perceptions of well-being within families of youths with intellectual disabilities in Saudi Arabia. *Children*, *11*(6), 644. https://doi.org/10.3390/children11060644	The Beach center FQOL scale was used with 148 parents and other relatives to examine emotional well-being, family interactions, and parenting in Saudi Arabia. Findings include variations in FQOL perceptions among family members, with fathers showing distinct levels of satisfaction. This study contributes to the development of culturally sensitive support strategies & policies, emphasizing the need for targeted interventions to enhance the well-being of these families.
3.	Alnahdi, G. H., & Schwab, S. (2024). Families of children with intellectual and developmental disabilities: Variables associated with family quality of life. *Children*, *11*(6), 734. https://doi.org/10.3390/children11060734	This study investigated FQOL predictors of 320 family members from the Riyadh region of Saudi Arabia. Participants' satisfaction with FQOL was at a moderate level. Severity, type of disability, and the mother's age and education were significant predictors of the FQOL.
4.	Bacherini, A., Gómez, L. E., Balboni, G., & Havercamp, S. M. (2024). Health and health care are essential to the quality of life of people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(2), e12504. https://doi.org/10.1186%2Fs12913-023-10206-2	This research article investigates the need for caregivers for individuals with intellectual disabilities and studies how their work in preventing and identifying issues and maintaining their quality of life is critical for their life expectancy and is rarely studied. They concluded that people with intellectual disabilities need health support to properly communicate needs and maintain a proper lifestyle.

5.	Blackmore, A. M., Mulhern, B., Norman, R., Reddihough, D., Choong, C. S., Jacoby, P., & Downs, J. (2024). How well does the EQ-5D-Y-5L describe children with intellectual disability?: “There’s a lot more to my child than that she can’t wash or dress herself.” *Value in Health*, *27*(2), 190-198. https://doi.org/10.1016/j.jval.2023.11.005	This qualitative study measured caregiver perceptions of the validity and suitability of the EQ-5D-Y-5L, a proxy reported scoring scale used to measure health-related quality of life for children with IDDs. 30 caregivers completed the **EQ**-5D-Y-**5L and** were interviewed for a total of 28 interviews regarding 17 total children with a variety of IDDs, including CP, ASD, and rare genetic disorders. Responses to interview questions found that caregivers consider the EQ-5D-Y-5L clear, concise, and largely relevant, but insufficiently comprehensive for this population.
6.	Boland, G., Potter, A. M., de Paor, E., & Guerin, S. (2024). Can natural supporters be fostered to support adults with intellectual disabilities to become local volunteers or to join mainstream leisure groups in Irish rural towns and villages? *British Journal of Learning Disabilities*. https://doi.org/10.1111/bld.12644	This study examined the experiences of six adults with ID who joined mainstream leisure clubs or became local volunteers, with support from a club member. A Valued Social Role Checklist developed from this study offers a tool when sourcing social roles.
7.	Buxton, H., Gomes, M., Gafoor, R., Taylor, Z., & Totsika, V. (2024). Measuring quality of life of adults with intellectual disabilities: Psychometric evaluation of the personal outcomes scale (POS) in the United Kingdom. *Journal of Applied Research in Intellectual Disabilities, 37*(2), e13189. https://doi.org/10.1111/jar.13189	This study evaluated the QOL of 310 adults with ID using the POS. This study looked at the differences in the POS system in the English language version and the United Kingdom version using first and second factor order models as well as multi-level models. The results indicated that there was a poor fit of the data throughout all models tested.
8.	Carter, E. W. (2024). Spirituality, disability, and quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1), e12458. https://doi.org/10.1111/jppi.12458	This article addresses the salience of spirituality & religion; their impact on QOL; complexities of addressing these areas among people with IDD; the ways in which they can be conceptualized and assessed; and implications for policy and practice.
9.	Cheng, S., Li, J., Li, Q., Li, X., & Luo, Y. (2024). Family quality of life of parents of children with intellectual disability: Do psychological stress and parental involvement matter?. *Journal of Intellectual Disabilities*, 17446295241254624. https://doi.org/10.1177/17446295241254624	This study examined interrelations between psychological stress, parental involvement, and FQOL in China (using Beach center’s FQOLS completed by 467 parents). Structural equation modeling indicated that psychological stress had a direct and indirect influence on FQOL. Physical and mental response and risk awareness had a positive direct effect on FQOL, & optimistic hope had a negative effect on FQOL.
10.	Diz, S., Jacinto, M., Costa, A. M., Monteiro, D., Matos, R., & Antunes, R. (2024, March). Physical Activity, Quality of Live and Well-Being in	The aim of this systematic review was to analyze whether physical activity, exercise,

	Individuals with Intellectual and Developmental Disability. In *Healthcare* (Vol. 12, No. 6, p. 654). MDPI. https://doi.org/10.3390/healthcare12060654	and sport can improve the quality of life for people with IDD. Fifteen articles from three databases were assessed using the Downs and Black scale. The researchers concluded that physical activity, exercise, and sport contribute to improving the well-being of people with IDD but stressed the importance of conducting more studies.
11.	Edwards, M., & Schippers, A. P. (2024). Expanding the quality of life paradigm: Contributions from the field of disability studies. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1), e12483. https://doi.org/10.1111/jppi.12483	This article considers the contributions from the field of disability studies to the conceptualization of QOL for people labelled with ID. Four elements (meaning of disability, relationality, participatory design and intersectionality) from the field of disability studies may be incorporated into an evolving QOL paradigm.
12.	Faragher, R., & Lloyd, J. (2024). Continuing conceptualising QOL through application to lives of young adults with Down syndrome. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1), e12479. https://doi.org/10.1111/jppi.12479	This article describes QOL domains for young adults with Down syndrome, identifying six key areas: physical well-being, emotional well-being, self-determination, material well-being, personal beliefs and development, and social inclusion. The authors concluded that there is a need to reconsider the roles of ICT and rights within these domains, suggesting that while domains are useful for research, they should be flexible with evolving societal values.
13.	Friedman, C., & Gilden, C. (2024). Treating employees with dignity, respect, and fairness: The impact on the quality of life of people With intellectual and developmental Disabilities. *Inclusion*, *12*(3), 156-171. https://doi.org/10.1352/2326-6988-12.3.156	This study examined the impact of human service providers treating their employees with dignity, respect, and fairness on QOL of people with IDD. Multilevel logistic regressions of data on Personal Outcome Measures (*n* = 3,898 people with IDD) and Basic Assurances (*n* = 387 providers) indicated when providers treated their employees with dignity and respect, people with IDD were more likely to have positive outcomes: health; continuity and security; realize goals; free from abuse and neglect; respect; decide when to share information; housing choice; fair treatment; rights; and choose services. How organizations treat their employees not only affects those employees but also impacts the QOL of people with IDD.
14.	Jalili, S., Martínez-Tur, V., Estreder, Y., Moliner, C., Gracia, E., & Fajardo-Castro, L. V. (2024). Trust and quality of life: A study in organizations for individuals with intellectual disability. *Research in Developmental Disabilities*, *151*, 104782. https://doi.org/10.1016/j.ridd.2024.104782	This study tested a trust-mediated model with 139 supervisors, 1101 team members, and 1468 family members. Our findings confirmed a cross-level mediation process. Supervisors' trust in their teams leads to teams' trust in their supervisors. This trust at the team level in

		turn is positively associated with organizational performance oriented to improving QOL of individuals with ID, reported by family members.
15.	Holmes, H. M., & Mortenson, W. B. (2024). What makes life better or worse: Quality of life according to people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *37*(5), e13280. https://doi.org/10.1111/jar.13280	This study examined the perspectives of 18 people with ID on the factors which improved or hindered QoL, using art-based photovoice methodology. Support from family, hobbies, activities and wellbeing such as rights, opportunities for friendships and relationships, taking care of bodies, education, pets, spirituality, culture, religion, being able to afford to live added QOL and factors such as inaccessibility, assumptions, negative behaviors, & stress decreased QOL. Staff had both positive and negative impact in their QoL.
16.	Kapsalakis, P., & Nteropoulou-Nterou, E. (2024). Perspectives of adults with intellectual disabilities on quality of life: A qualitative study. *International Journal of Environmental Research and Public Health*, *21*(9), 1186. https://doi.org/10.3390/ijerph21091186	Experiences of occupational participation of adults with ID explored through lenses of the Model of Occupational Justice (MOJ) and Critical Theory to develop an occupation-centered model of QoL. Qualitative data gathered from interviews with 13 adults with ID informed the preliminary model of O-QoL with 3 core O-QoL domains: (i) social well-being, (ii) emotional-physical well-being, and (iii) material adequacy. Key indicators of O-QoL were leisure and social activities, while socioenvironmental factors such as occupational deprivation were aggravating. Model of O-QoL (version 1) could be a valuable alternative conceptual framework of QoL in the field of IDs.
17	Lui, M., Lau, G. K. B., & Wong, P. K. S. (2024). The associations among executive planning, self-determination, and quality of life in adolescents with intellectual disability. *Journal of Intellectual Disability Research : JIDR*, *68*(1), 53–63. https://doi.org/10.1111/jir.13091	Cross-sectional study of 79 individuals (17-20 years) with mild ID on how executive functions (working memory, inhibition and executive planning) was associated to self-determination and QOL. QOL had a negative association with executive planning & a positive association with self-determination. There was no association between working memory with inhibition and non-verbal IQ with self-determination. Causal relationships between these variables in adolescents with ID need further study.

18	Marsack-Topolewski, C., & Wright, K., DiZazzo-Miller, & Samuel, P.S. (2024). Careers and Quality of Life: Comparing perceptions of compound and noncompound caregivers. *Occupational Therapy in Health Care.* https://doi.org/10.1080/07380577.2024.2400526	This paper used the electronic version of the international FQOL survey to compare differences in QOL and FQOL of compound and 113 noncompound caregivers and describe how career-related dimensions influence the global FQOL. Examination of survey data from 77 compound and 113 noncompound caregivers indicated that compound caregivers had lower QOL, global FQOL, and worse career outcomes than noncompound caregivers
19	Morán, M. L., Gómez, L. E., Balboni, G., Bacherini, A., & Monsalve, A. (2024). Quality of life in children and adolescents with cerebral palsy and intellectual disability: Predictors and personal outcomes. *Child Indicators Research*, *17*(1), 123-143. https://doi.org/10.1007/s12187-023-10079-1	This study examines the influence of individual and environmental variables on the QoL of 165 children (4-21 years) with CP and ID who were receiving support from 42 Spanish organizations. The KidsLife Scale was used to measure QoL and the findings are beneficial for those working in fields related to pediatric disability, rehabilitation, and QOL improvement strategies.
20	Meena, M. K. (2024). Enhancing quality of life for individuals with intellectual disabilities: Strategies and interventions. *Medalion Journal: Medical Research, Nursing, Health and Midwife Participation*, *5*(2), 86-92. https://doi.org/10.59733/medalion.v5i2	This article examines the interventions and approaches for enhancing QOL of individuals with ID. This study explores various methods of healthcare, education, support, and social necessities alongside their efficiency through case studies and recent practices to present an overview of valuable interventions.
21	Miezah, D., Eshun, E., & Ansah, K. O. (2024). Family quality of life of Ghanaian families raising people with intellectual disability [PWID]. *Journal of Psychology in Africa*, *34*(4), 388-394. https://doi.org/10.1080/14330237.2024.2413334	This study examined FQOL of were 176 Ghanaian parents using the Beach Center FQOL Scale. Parents were satisfied with overall FQOL, and the least satisfied with FQOL subdomains were disability-related support, physical/material well-being, & emotional well-being. Female parents reported a higher overall FQOL than male parents. Parents of male children with ID reported a higher overall FQOL, compared to those with female children with ID.
22	Mumbardó-Adam, C., Vicente, E., & Balboni, G. (2024). Self-determination and quality of life of people with intellectual and developmental disabilities: Past, present, and future of close research paths. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1), e12460. https://doi.org/10.1111/jppi.12460	This article discusses how self-determination is an essential concept in the QOL program & highlights areas of future research development to strengthen understanding of QOL & self-determination.
23	Nieuwenhuijse, A. M., Willems, D. L., & Kruithof, K. (2024). Understanding quality of life of persons with profound intellectual	Through a qualitative approach, the authors aim to understand the unique factors that contribute to the well-being & life satisfaction

	and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1), e12473. https://doi.org/10.1111/jppi.12473	of this population. The study also highlights the importance of personalized care & need for policies that address specific needs & experiences of people with PIMD.
24	Neuman, R., Reiter, S., & Brown, R. I. (2024). The humanistic perspective as "a lighthouse" for the perception of QOL/FQOL and its application. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1), e12485. https://doi.org/10.1111/jppi.12485	This article described the role of the *humanistic* perspective of QOL that does not appear to be formally or directly structured into models of QOL. Although many researchers & practitioners have considered a humanistic approach, the core beliefs & elements on humanism have received detailed attention in QOL literature. This article proposes humanistic philosophy to be the basis for defining humanistic theoretical principles & guidelines for practice, & to be an important vehicle for operationalizing & applying QOL.
25	Paswan, A., & Kumar, P. (2024). Efficacy of parent training programme in enhancing quality of home and community living of individuals with intellectual disability in Haryana (India). *Journal of Psychosocial Research*, *19*(1), 1-8. http://doi.org/10.32381/JPR.2024.19.01.7	The study compares the effectiveness of parent training programs on QOL of children with ID (120 study group & 120 control group). Pre- and post-test data from parents using Binet-Kamat Test of Intelligence & QOL Scale for Persons with Disabilities showed significant improvement in Quality of Home and Community Living dimension of QOL of children in study group, & perceptions of parents on QoL of children with ID.
26	Samuel, P. S., Anderson, N., Marsack-Topolewski, C. N., & Milberger, S. (2024). Electronic version of the Family Quality of Life Survey (eFQOLS): Reliability and validity for families of individuals with disabilities and chronic health conditions. *Occupational Therapy in Health Care*, 1-18. https://doi.org/10.1080/07380577.2024.2343676	This study evaluates the psychometric properties of the modified eFQOLS. The responses from 272 caregivers of people with ID & chronic conditions. The internal factor structure of the FQOLS demonstrated adequate validity, reliability as a measure of internal consistency, & can be an efficient method to measure FQOL.
27	Samuel, P. S., Janks, E., Anderson, N. S., Bray, M., Topolewski, C., & Milberger, S. (2024). Peer-mediated family support project: Evaluation of changes in family quality of life. *Developmental Disabilities Network Journal*, *4*(1), 9. https://doi.org/10.59620/2694-1104.1091	The study reports that families benefitted from participating in Michigan Older Caregivers of Emerging Adults with Autism and Neurodevelopmental Disabilities (MI-OCEAN), a program which assists aging caregivers of adults with IDD using peer mentors. A quasi-experimental research design with pretest and posttest data gathered from 82 caregivers indicated that significant changes observed in 8 of the 9 FQOL domains and global FQOL. Correlation analysis indicated that 5 of the 9 domains were significantly associated with changes in global FQOL. Multiple regression analyses indicated that about 16% of the

		improvement in global FQOL could be explained by the FQOL domain of informal support.
28	Santilli, S., Ginevra, M. C., Bishop, C., & Nota, L. (2024). After us, together with us: Quality of life in adults with disabilities in an inclusive and sustainable future. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(4), e12527. https://doi.org/10.1111/jppi.12527	This contribution provides an overview of QOL for adults with ID, examines the relationship of QOL with sustainability, inclusion, and social justice, and examines the contextual factors that contribute to promoting or hindering QOL of individuals with ID.
29	Savaş, E. H., Aydin, A., & Bertan, İ. (2024). The effect of transition to adulthood training program for mothers of young adults with intellectual disability on family quality of life and perceived stress level: A pilot randomized controlled study. *Journal of Intellectual Disabilities*, 17446295241259100. https://doi.org/10.1177/17446295241259100	This RCT evaluates the impact of the Transition to Adulthood Training Program (TATP) on FQOL and perceived stress levels among 33 mothers (18 = study group, 15= control group) using Beach Center FQOL scale & Perceived Stress Scale. TATP was effective in improving FQOL & decreasing maternal stress.
30	Shen, X., Huang, P., Nie, B., Su, M., Liu, D., Guo, Y., & Zheng, L. (2024). An adapted physical activity program for adolescents with an Intellectual Disability: An International Classification of Functioning, Disability, and Health Perspective. *Life*, *14*(10), 1314. https://doi.org/10.3390/life14101314	38 adolescents with ID were randomly allocated into either a 6-month intervention group, which participated in the tailored APA program, or a control group, which received standard physical education. The findings demonstrated significant improvements in the IG's gross motor development, locomotor, object control, & QOL scores relative to controls. Substantial gains were observed in physical function measures, including upper and lower limb strength as well as cardiorespiratory fitness. Strong positive correlations were noted between QoL and physical functioning. This study underscores the importance of tailoring physical activity programs for adolescents with ID and guidance for future interventions.
31	Sorkhi, N., Akbarzade, I., Nedjat, S., Khosravi, M., Nazemipour, M., Memari, A. H., & Mansournia, M. A. (2024). Validity and reliability of the Persian version of the world health organization quality of life disabilities module. *Journal of Intellectual Disabilities*, *28*(1), 240-260. https://doi.org/10.1177/17446295221123867	This study assessed the validity & reliability of the WHOQOL-DIS-ID using a sample of 118 adults with ID. Persian version of the WHOQOL-DIS-ID shows acceptable validity & reliability. Predictors of QOL included periodic check-up, number of friends, entertainment outside the home, parental separation, physical activity, unmet needs score, caregiver's mental health status, & available facilities.
32	Taylor, S., David, J., Dew, A., & Watson, J. (2024). The role of microboards [MB4C] in enhancing quality of life for children with	The study examines MB4C, a family-centered practice addressing 5 factors: (1) support from

	intellectual disability and their families. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1), e12474. https://doi.org/10.1111/jppi.12474.	family & friends; (2) relationship between family members & how they support each other; (3) health, emotional, physical & material well-being; (4) support from service providers & adequacy of services; (5) level of disability & diagnosis. Qualitative data from 23 participants (21 board members and 2 staff members), representing 13 microboards spanning an average duration of 2.29 years (2-22 years) indicated that that the MB4C model equipped the family to understand the vision of the individual with IDD, & the formal and informal networks of support provided families with knowledge to support the child's future and improved their FQOL
33	Verdugo, M. Á., & Schalock, R. L. (2024). From a concept to a theory: The six eras of quality of life research and application. *Research in Developmental Disabilities*, *150*, 104763. https://doi.org/10.1016/j.ridd.2024.104763	A review of the literature to describe the evolution of QOL concepts over 6 eras beginning from the early 1990s. The first 3 eras focused on formulating principles, model development, & instrument construction for application of the QOL concept, & the last 3 eras involved QOL application, theory development, & confirmation. The article describes the conceptual development of QOL in IDD, & the connection between QOL & the supports paradigm was underscored.
34	Verdugo, M. Á., Schalock, R. L., & Gómez, L. E. (2024). The quality of life supports model as a major component in applying the quality of life paradigm. *Journal of Policy and Practice in Intellectual Disabilities*, *21*(1), e12468. https://doi.org/10.1111/jppi.12468	The QOL Support Model is a well- integrated system to deliver the QOL paradigm as it provides a theory-based & professionally sound framework for supports provisions, person-centered outcomes evaluation, organizational transformation & systems change. The model could be implemented to bring changes in policies and practices to enhance the QOL.
35	Verhaar, L., Dijkxhoorn, Y. M., de Sonneville, L., & Swaab, H. (2024). A three-years follow-up of extra intensive support for individuals with intellectual disability and severe challenging behaviour in the Netherlands. *Journal of Intellectual Disabilities*, 17446295241252918. https://doi.org/10.1177/17446295241252918	This longitudinal study evaluated individuals with ID with challenging behaviors, receiving two types of support: Intensive support (IS, n = 117) and extra intensive support (IS+, n = 35). Outcomes were measured using the Developmental/IQ test, Challenging behaviour: Developmental behavioral checklist – Adult, Adaptive behaviour: Vineland Adaptive Behavioral Scale, Vineland Screener and San Martin Scale**.** Participants in the IS+ group had fewer challenging behaviors but no changes in QOL, whereas the IS group had better QOL,

		and both groups showed no changes in adaptive behaviour.
36	Wang, Z., Sommerlad, A., Hassiotis, A., Richards, M., & Livingston, G. (2024). Mid-life social participation in people with intellectual disability: The 1958 British birth cohort study. *Plos one*, *19*(5), e0302411. https://doi.org/10.1371/journal.pone.0302411	This longitudinal cohort study followed participants from the age of 11 (N = 14,094) to the age of 50 (N = 8448). They reported that adults with IQ above 85 had more social contact & better QOL at age 50, and the cognitive decline by age 50 was mild in the participants in the study. Participants had more positive relationships within the family compared to outside the home. The need to build confiding relationships can improve QOL in individuals with ID.
37	Yadav, G. K., Rashwan, H. A., Vidales, B. M., Abdel-Nasser, M., Oliver, J., Nandi, G. C., & Puig, D. (2024). A data-driven model to predict quality of life dimensions of people with intellectual disability based on the GENCAT Scale. *Social Indicators Research*, *172*(1), 81-97. https://doi.org/10.1007/s11205-023-03263-x	The study shows the promise of the machine and deep learning-based models, particularly Deep Neural Networks (DNNs), as a more effective and precise substitute for the GENCAT scale for calculating the 8 QoL dimensions in people with ID. The results open the door for better QoL evaluations and individualized interventions to improve this population's well-being as they age.