The University Of Queensland
AUSTRALIA

CREATE CHANGE

Report of the Down Syndrome Research Program

2024

Contents

From the Associate Dean (Research)

The University of Queensland (UQ) has had a long and very proud history of research in intellectual disability. In 1952, the Fred and Eleanor Schonell Special Education Research Centre initially opened as the Remedial Education Centre. Hosted in the School of Education at UQ, the Centre conducted numerous studies in disability research, with research outcomes being life-changing for individuals, parents, siblings, families, teachers, schools, communities, and society.

Much has changed to the disability landscape since 1952, for example, de-institutionalisation, assisted community living, inclusive education, and assistive technology. Our UQ researchers have been at the forefront of many of these debates that have changed attitudes, beliefs and ways of life for individuals with disabilities. Unequivocally, the Down Syndrome Research Program has provided a substantial evidence-base for understanding individuals with intellectual disabilities and enhancing quality of life choices and opportunities.

The vital importance of ongoing research into Down syndrome

The Faculty of Humanities and Social Sciences is incredibly proud to host the Down Syndrome Research Program, and its world-class research. The mission of the Down Syndrome Research Program closely aligns with the faculty research mission where our core purpose is to deliver for the public good through excellence in education, research and engagement with our communities and partners. The research being conducted by the Down Syndrome Research Program has made significant contributions to society and has endured in an often-overlooked area of scholarly work. Yet, the research addresses some of the most fundamental issues facing society – issues of social and community inclusion, acceptance of difference, diversity, and disadvantage, inclusive schooling for all children and young people, and informed decision making with increasing genetic screening and testing. The applicability of the research findings is far-reaching to a range of disability fields, to researchers in many disciplines, and to the wider community, with many issues still needing to be resolved and researched.

The current focus of the team is on two critical issues facing people with Down syndrome and those who support them: improving the educational experience of learners with Down syndrome in inclusive settings and exploring ways to enhance quality of life for adults with Down syndrome as they age. The impact of this work will have global benefits.

I congratulate the research team who have worked with rigour, dedication and a life-long commitment to disability research and I encourage you all to continue to advocate for Down Syndrome research and to advance research knowledge and create change in awareness, understanding and acceptance of diversity for all in our society.

Professor Annemaree Carroll
Associate Dean (Research)

From the Director

DSRP – 45 years and going strong!

In 1978, a visionary team of researchers at the University of Queensland initiated a remarkable research idea. They were curious about family life of babies born with Down syndrome in the greater Brisbane area at a time when babies were no longer being placed routinely in institutions for life. That idea grew to become a program of research spanning over 45 years, following the first generation of people with Down syndrome in modern times to be cared for by their families, educated at school and growing up to live in the adult community.

Dr Anne Jobling, one of the original researchers on the DSRP, has written about the history of the longitudinal study for this report.

Over the years, new projects have brought new participants into the program involving more than 200 families.

The longitudinal study is now just one part of our significant program of research.

Research in the DSRP continues to develop, responding to issues arising in the field of Down syndrome, often raised by participants and their families.

Research highlights

In the pages to follow, current research projects and research outputs of various forms are showcased.

We also have higher degree research students contributing to the work of the program. Numbers of people with Down syndrome are growing in Australia, due in part to increasing longevity[2]. Ageing is an area of significant research interest in the field and is a part of the DSRP. We are also interested in contributing research to ensure people with Down syndrome of all ages and their families enjoy the best possible quality of life. We have current work exploring education across the lifespan – inclusive practices, mathematics learning, and adult quality of life. We are also investigating current issues including the impact of genetics screening and testing.

An important development in our work has been the opportunity through grant funding to employ people with Down syndrome to work as research assistants. This was a natural progression of our work. It did not take long for us to recognise the invaluable input our researchers were making to the work. Their perspectives on the research issues have added important contributions to the studies.

Future plans

This year, Down Syndrome Australia will host the World Down Syndrome Congress on behalf of Down Syndrome International in Brisbane. Our research features in the program with researchers giving plenary addresses, workshops, papers and posters. We have much to tell! We are very excited that our research assistants are presenting their work.

We are taking our research findings into the community in a variety of ways, through webinars, virtual conference contributions, and podcasts and through more traditional ways of publications. I hope you enjoy reading about this work in the pages of this report.

Professor Rhonda Faragher AO
Director

2 de Graaf, G., Skladzien, E., Buckley, F., & Skotko, B. (2022). Estimation of the number of people with Down syndrome in Australia and New Zealand. Genetics in Medicine, 24(12), 2568-2577. https://doi.org/10.1016/j.gim.2022.08.029

Research Team and Staff

Professor Rhonda Faragher AO

B.Sc., Grad.Dip.Ed., B.Ed.St.(Hons1), PhD, SFHEA, FIASSIDD

Profile
researchers.uq.edu.au/researcher/16169

Director

Rhonda Faragher is the Director of the Down Syndrome Research Program within the School of Education in the Faculty of Humanities and Social Sciences and Professor in Inclusive Education. She has internationally recognised expertise in the mathematics education of learners with Down syndrome. In her research and teaching, she works to improve the educational outcomes of students who have difficulties learning mathematics, for whatever reason, including through educational disadvantage. Beyond mathematics education, she has expertise in inclusive education in a range of contexts, including secondary classrooms.

She is an appointed Board member to the Academy on Education, Teaching and Research of IASSIDD - the International Association for the Scientific Study of Intellectual and Developmental Disability and Chair of the Down syndrome Special Interest Research Group of IASSIDD. She is Co-Editor in Chief of IASSIDD's journal, the Journal of Policy and Practice in Intellectual Disabilities. In 2019, she was made a Fellow of IASSIDD. She is Vice-President of Down Syndrome International and a Director of Down Syndrome Australia.

Professor Faragher is a Senior Fellow of the Higher Education Academy and has received a number of awards for her work including the 2020 University of Queensland Award for Excellence in Community, Diversity and Inclusion; ; a Commonwealth of Australia Endeavour Executive Award, the 2011 Mathematics Education Research Group of Australasia Research Award and the Alderson award for services to people with Down syndrome. In 2023, she was appointed an Officer of the Order of Australia.

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Dr Jan Lloyd

Dip ECE, BECE, MPhil, PhD

Program Manager

Jan Lloyd has been a part of the Down Syndrome Research Program for many years and is the now the Program Manager. She is a research administrator for the DSRP and the Latch-on program.

Jan has a Diploma of Early Childhood Education, Bachelor of Early Childhood Education and a Master of Philosophy that focused on computer literacy for young adults with intellectual disability. Her doctoral studies investigated the NDIS planning process for adults with intellectual disability and their families.

She has been working as a research administrator in the Down Syndrome Research Program at The University of Queensland with the major role of maintaining contact with participants and families involved in the research program.

Dr Lloyd's research interests include literacy, numeracy and post school opportunities for adults with intellectual disability.

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Associate Professor Karen Moni

BEd, PostGrad Dip, PostGrad DipEd, BA (Hons), PhD

Profile
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Board member, Past Director

Karen Moni has had extensive experience teaching and researching in the field of English and literacy education. Her research interests include adolescent literacy and literature, literacy and young adults with intellectual disabilities, teacher education and teaching and learning in higher education.

Associate Professor Moni is also the Executive Director of Latch-On, a research and teaching program focusing on literacy and young adults with intellectual disabilities, and continues to research in the area of intellectual disability.

Associate Professor Moni has received a number of research grants from The University of Queensland (Training and Employment, UQ Early Career Researcher and UQ FirstLink Scheme), ARC (ARC Linkage Projects and ARC Discovery Projects), The Corporation of the Trustees of the Roman Catholic Archdiocese of Brisbane and Commonwealth Department of Education (Training and Youth Affairs).

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Professor Monica Cuskelly

BA(Hons); GradDipEd; MEdStud: MAppPsych; PhD

Profile
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Board member, Past Director

Monica Cuskelly is Director of Research of the Applied Research Centre for Disability and Wellbeing, a joint initiative of Possability Group and the University of Tasmania. The Centre was established for the purpose of creating new knowledge that can be used to improve the lives of individuals with developmental, intellectual or cognitive disabilities. Professor Cuskelly was at the University of Queensland for a number of years, during which time she contributed to the activities of the Down Syndrome Research Program in a number of capacities, including filling the role of Director.
Her research interests focus on lifespan developmental issues related to those with intellectual and developmental disability with a specific interest in the development of individuals with Down syndrome. The family experience of those with a family member with Down syndrome (or other developmental disability) is also a focus of her research. Currently, her work focusses on the lives of adults, including social and emotional dimensions such social connection and loneliness.

Professor Cuskelly was elected as a Fellow of the Academy of Social Sciences in Australia in 2022.

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Dr Anne Jobling

BEdSt, PhD, ASM

Profile
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Past Director

Anne Jobling is an Adjunct Senior Lecturer and honorary researcher in the School of Education at the University of Queensland. She is a well-respected teacher and researcher in the area of intellectual disability, and has developed a unique understanding of children and adults with Down syndrome and their families due to her long term commitment to and association with the field. For many years she worked on and directed the Down Syndrome Research Program, and also became the Executive Director of the Latch-On program that she developed with Dr Karen Moni.

Dr Jobling has presented at numerous international and national conferences including keynote addresses. Her research foci in education have been in motor development and health-related issues of those with Down syndrome as well as the literacy development of individuals with intellectual disabilities. She has published several books and numerous book chapters, and has over 60 peer-reviewed articles, many with international researchers. She has been successful with several Australian Research Council grants.

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Adjunct Researchers

Associate Professor Jasneek Chawla

MBBS, BSc(Hons), PhD, FRAC

Profile
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Jasneek Chawla is a Paediatric Respiratory and Sleep Medicine Physician at the Queensland Children's Hospital and a Senior Lecturer with the School of Clinical Medicine.

Dr Chawla is active in Clinical Sleep Medicine Research and has a special interest evaluating the impact of sleep disorders in children with disability. Her PhD work evaluated the impact of sleep interventions on functional, cognitive and behavioural outcomes in children with Down syndrome. She is also assessing the efficacy of a tailored behavioural sleep intervention for children with Down syndrome. She was awarded a 3-year Advancing Clinical Research Fellowship for her PhD studies and previously received a Research Entry Scholarship from The Royal Australasian College of Physicians. Other research includes exploring the role of alternative treatments for children with Obstructive Sleep Apnoea and optimization of the utilization of continuous oximetry in infants with chronic neonatal lung disease.

Dr Chawla is a member of the Australasian Sleep Association and is involved in several activities within the organization. She is deputy chair of the ASA Conference Committee, a member of the Paediatric Council Committee, the Paediatric Representative for the GP Education Sub-Committee and ASA NATA Accreditation Medical Advisory Committee. She is also leading the Paediatric Home Ventilation Guideline Working Group that is revising existing guidelines. Dr Chawla is also a speaker for The Sleep Health Foundation and has undertaken several talks within the local community to promote healthy sleep awareness.

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Dr Catherine Franklin

MBBS, FRANZCP

Profile
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Cathy Franklin is a psychiatrist who leads the Queensland Centre of Excellence in Autism and Intellectual Disability Health, based at Mater Hospital. This includes the clinical service, Mater Intellectual Disability and Autism Service, the Wild Centre of Excellence in IDD Mental Health, and the UQ research centre, the Queensland Centre of Intellectual and Developmental Disability.

Cathy is a clinician researcher, with special interests in Down syndrome and building the capacity of mainstream health staff in intellectual and developmental disability health. She leads her centre's contribution to the Down syndrome research consortium led by Professor Brian Skotko, of Massachusetts General Hospital, and this consortium has produced several publications in recent years.

Cathy also chairs the Regression and Mental Health workgroup of the Down Syndrome Medical Interest Group-USA with Dr Eileen Quinn. Cathy and her team lead several large scale grants, including the EASY Health project, the NHMRC funded Bridge to Better Health project, and the centre's role as Health Service Delivery team lead of the National Centre of Excellence in Intellectual Disability Health.

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Dr Kate Power

PhD

Profile
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Kate Power is a researcher and lecturer at The University of Queensland Business School. Her expertise is in critically evaluating how people and organisations use language to communicate about themselves and shape the world around them. She is committed to doing research that promotes justice and equity, and helps government, the media, and industry communicate for the common good.

Her current research explores sustainability in the arts and culture sector, news reporting on violence against women and girls, and COVID-19 crisis communication.

She has recently collaborated with various peak bodies in the Australian arts and culture sector such as Theatre Network Australia, and arts companies of various sizes (e.g., Queensland Ballet and La Boite Theatre) to develop a free peer coaching program known as "Creating out Loud." This program builds networks of mutual support for artists and arts workers across all levels of the arts and culture sector.

Enriching the arts and culture sector is of high importance to Kate. In 2021, she was awarded an Advance Queensland Industry Research Fellowship to support arts workers recovering from the COVID-19 pandemic.

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Professor Ernst Wolvetang

PhD

Profile
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Ernst Wolvetang is an international leader in stem cell bioengineering. He is a prolific author with over 26 000 citations to his work. He serves on scientific advisory boards of Mission Massimo, Genetic Cures for Kids, Brash-AT, CCRM Australia, and the Australian Functional Genomics Network.

Prof Wolvetang is a senior group leader at the Australian Institute for Bioengineering and Nanotechnology, leads the UQ node of the Australian Phenomics Initiative, and is director of the Australian Organoid facility at the University of Queensland. His research team employs human induced pluripotent stem cell derived brain organoids as in vitro disease models for studying neurological diseases.

Leveraging these "human brain in a dish" models and advanced genome engineering approaches he aims to understand how genetic mutations, ageing, and environmental factors such as viruses, cause diseases that affect the brain. These models, in conjunction with automated robotic systems, single cell analysis methods, and functional read-outs on multi-electrode arrays, are next used to identify and test therapeutic approaches that can improve patient health outcomes.

Professor Wolvetang has been instrumental in establishing and enabling the technology for derivation of induced pluripotent stem cells across Australia. Professor Wolvetang made the strategic decision to focus on the generation of induced pluripotent stem from patients to avoid the need for live human cells. Induced pluripotent stem cells have the ability to generate every cell type of the human brain in unlimited amounts. Induced pluripotent stem cells combined with emerging technologies such as CRISPR-based genome editing offers a unique opportunity to study the role of individual genes and combinatorial gene regulatory pathways in the aetiology of monogenic and complex brain disorders.

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Research Activities

The Down Syndrome Research Program has encompassed many research projects over the years, responding to the needs of our participant groups as well as investigating issues affecting people with Down syndrome more broadly. Being a research centre in the School of Education, our projects are particularly concerned with improving the education outcomes of learners with Down syndrome across the lifespan.

Recent and current projects include:

1. LYLAC: Learning Year Level Adjusted Curriculum. Reasonable Adjustments to Secondary Mathematics for Students with Intellectual Disabilities
2. British Academy Visiting Fellowship
3. Latch-on
4. Quality of Life of Young Adults with Down syndrome (Gen Z project)
5. Creating Out Loud – Easy Read version
6. "We Need to Talk": Ethical, Legal and Social Issues of Genomics in the context of disability.
7. Down Syndrome and Sleep
8. Using Organoids to Investigate Genomics and Down Syndrome

In the pages to follow, we provide a brief overview of the projects with selected outputs to date. For more information, you are very welcome to contact the lead researcher by the contact email provided.

1. Learning Year Level Adjusted Curriculum (LYLAC): Reasonable Adjustments to Secondary Mathematics for Students with Intellectual Disabilities

Project Lead
Professor Rhonda Faragher

This project, funded by the Australian Research Council's Linkage Project scheme, has involved research in five secondary schools.

Our partners in this project are: Edmund Rice Education Australia; Association of Independent Schools, Queensland; Redland Bay College; Ripley Valley State Secondary College; St Aidan's Anglican Girls School; St Joseph's College, Nudgee; and St James College.

Our work is directed towards understanding how the secondary mathematics curriculum and assessment can be adjusted to remove barriers to the attainment of learning outcomes of junior secondary mathematics as specified in the Australian Curriculum.

The project involves key aspects:

1. A survey to understand how Australian secondary mathematics teachers view the inclusion of students with intellectual disabilities in their classrooms.
2. Cycles of classroom lesson development and observation in the five project schools.
3. Professional learning program including a survey of project teachers, capturing their expertise, attitudes and beliefs with respect to including students with intellectual disability in their mathematics classes.

We have undertaken annual teacher professional learning workshops during which we have included sessions on specific aspects of intellectual and developmental disability, impacts on learning mathematics, teaching approaches and strategies, and sharing of expertise. Then, twice each year, we have undertaken lesson adjustment planning and school observations. After the lesson observations, we have recorded interviews with teachers discussing the adjustments they made and their reflections on the lessons.

Emerging themes from our study include:

- Opportunities to listen to other students supports low attainers
- Adjustments can be very simple
- Adjustments available to all make the lesson more accessible to all
- Adjustments do not replace the need for high quality teaching for all
- Equipment available in the classroom allows adjustments to be made on the spot
- Barriers (which might be perceived)
  - Time
  - Coverage vs student learning
  - Fixed mindset
  - Assessment constraints
  - Additional support for teachers is helpful, such as learning support assistants or additional teachers.

Selected Outputs

Beswick, K., (2024). MAT annual conference. 'Charting a Course for a Digital World' 31 May – 1 June, 2024

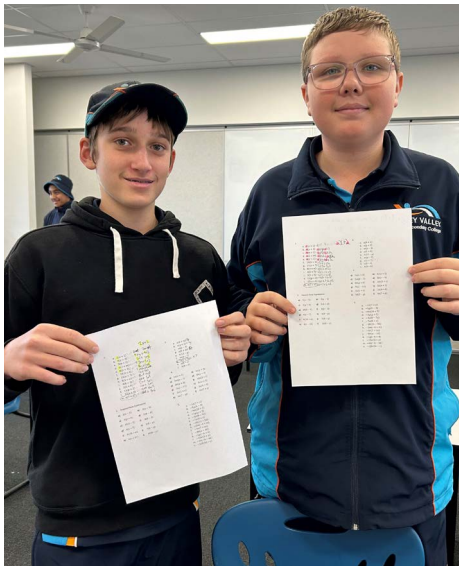
Beswick, K., Faragher, R., & Cuskelly, M. (2024). Reasonable adjustments to secondary school mathematics: Creating opportunities for students with intellectual and developmental disabilities. ICME-15: Come and be counted! Sydney, Australia.

Faragher, R. (2024). Adjusting the Australian Curriculum (2024). Keynote presentation DSV conference Authentic Inclusion in Schools on 4th March 2024

Faragher, R. (2024). Planning adjustments to the curriculum in mathematics. Proyecto AE23-00318: Adaptar el curriculum de matemáticas para incluir a todos los estudiantes. [Zaragotha, Spain, virtual training]

Faragher, R. (2024). Making learning adjustments. Workshop presented for the Learning Support Staff of Catholic Education Rockhampton Diocese, 30 May, 2024.

Faragher, R., Cuskelly, M., Lloyd, J., & Beswick, K. (2024). Making adjustments to secondary mathematics for students with IDD: Just do it! IASSIDD 17th World Congress, Chicago, 5-8 August, 2024.



2. British Academy Visiting Fellowship

Project Lead
Dr Rhonda Faragher

In 2023, Rhonda Faragher was awarded a Visiting Fellowship from the British Academy to undertake a project in collaboration with Professor Karen Watchman at the University of Stirling in Scotland.

The fellowship enabled the development of a project to study the quality of life of adults with Down syndrome as they age.

Down syndrome almost universally leads to a type of dementia due to the impact of the triplication of chromosome 21, where the genetic basis Alzheimer's disease lies. Much research has been undertaken to find cures or treatments. However, little research exists that investigates the value of preventative measures or ways to enjoy ageing, even with dementia. As a result, people with Down syndrome sometimes worry about getting old. For others, there is no preparation for getting older or for age-related changes.

The Fellowship resulted in a research proposal to study ageing of adults with Down syndrome in a longitudinal study that would have global significance.

A feature of the design is the involvement of people with Down syndrome as collaborators in all phases. In Scotland three people with Down syndrome were employed to guide the development of the proposal.

The proposal features collaboration with a team of researchers with expertise in Down syndrome, intellectual disability, dementia, and ageing around the world. This project will establish a partnership for ongoing collaborative research that will improve the quality of life of older adults with Down syndrome.

3. Latch-On

Project Leads
Dr Anne Jobling,
Associate Professor Karen Moni

Latch-On is a post-school program for adults with intellectual disability. It was developed and researched over five years by two researchers, Dr Anne Jobling and Associate Professor Karen Moni in the UQ School of Education. It is a two-year program, undertaken two days a week that promotes and recognises lifelong learning through a focus on the development of literacy and numeracy. Our research supports the view that when adults with intellectual disability are provided with opportunities to broaden their education through appropriate teaching and learning strategies, they continue to develop and improve their abilities and skills.

After the initial research and the development of the program resources, the program was commercialised through UniQuest (The University of Queensland's commercial arm) and a license partnership for the program was developed with the Endeavour Foundation of Queensland. This organization continued with their license for ten years. During those years a cluster of Community Colleges in British Columba Canada and the Down Syndrome Research Foundation in Vancouver also ran the program. Over the last 13 years an Irish parent association Down Syndrome Ireland (DSI) also became partners. DSI are currently delivering Latch On at their Education and Training Board sites (Irish equivalent of TAFE). Locally, DSQ held a licence and worked in partnership with the UQ team for two years to deliver the program in several sites in Southeast Queensland.

The Latch-On team (A/Prof Karen Moni, Dr Anne Jobling and Dr Jan Lloyd) have presented the program's findings in peer-reviewed articles and at many national and international conferences and have had a series of successful research visits to Ireland. Through their partnerships, the UQ team collects data and translates the research results into practice that is shared when working with partner community organisations and the wider disability community.

Contact:
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UNIQUEST

Selected Outputs

Moni, K., Jobling, A., & Baffour, B. (2018). Literacy learning outcomes in a longitudinal study of a post-school literacy education program for young adults with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities, 15(2), 155-165.

Jobling, A., Moni, K., & Lloyd, J. (2019). Adults with ID and their literacy learning: Strategies for success. Paper presented at the Future4 All World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Glasgow 6-9th August 2019.

Lloyd, J., Jobling, A., Moni, K., Martin, L., & Scanlon, I. (2019). Enhancing quality of life through literacy learning across the lifespan: The case study of a 65 year old woman with Down syndrome. Paper presented at the Future4All World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Glasgow 6-9th August 2019.

4. Stepping out in the World: Quality of Life of Gen Zs with Down syndrome

Project Lead
Dr Rhonda Faragher

Expectations for young people with Down syndrome used to be very low: persistent myths and outdated views of the capacities of people with Down syndrome meant that opportunities to attend local schools, gain employment and live independently were rarely possible. This has changed. Now there is a new generation of people with Down syndrome who may experience life in new ways. In this project, we gathered data on how 18–30-year-old adults with Down syndrome experience their lives.

This project was co-designed from the grant proposal stage with people with Down syndrome. We received funding from the National Disability Research Partnership. The study involved 26 interviews and five focus groups with people with Down syndrome, to understand how they live their lives. All data were collected through interviews and focus groups that were led by researchers with Down syndrome, who were trained as part of the project.

The outcomes of this research have been shared with the Down syndrome community, the research community, policy makers and professionals who interact with people with Down syndrome. This research will change how people understand the lives of young people with Down syndrome and start to tackle some of the barriers and attitudes that stand in the way of high expectations and better quality of life.

> *"It's not about being kind or in any way tokenistic — this employment strategy is absolutely because these individuals are doing work that we simply cannot do without their contribution. We need their expertise and working with this group of people has been just brilliant."*

Selected Outputs

In the media

University of Queensland hires assistants living with Down syndrome for Gen Z study. https://www.abc.net.au/news/2022-03-31/uq-hires-four-new-employees-with-down-syndrome/100950152

'We're awesome legends': Global focus on UQ's Down Syndrome research. https://www.abc.net.au/listen/programs/brisbane-mornings/uq-down-syndrome-study/13819322

Young adult researchers with Down syndrome hoping to change the narrative. ABC 7.30 https://youtu.be/I5B3O1E-6bk?si=SZIoIR1jak2xjT3F

Podcasts

Faragher, R., Lloyd, J., Pettigrew, A., & Faragher, R. (2023). Zest for Life. Brisbane, Australia: The University of Queensland. https://omny.fm/shows/living-with-down-syndrome-advice-from-gen-zs/zest-for-life

Faragher, R., Lloyd, J., Pettigrew, A., & Faragher, R. (2023). How to communicate with people with Down Syndrome. Brisbane, Australia: The University of Queensland. https://omny.fm/shows/living-with-down-syndrome-advice-from-gen-zs/how-to-communicate-with-people-with-down-syndrome

Faragher, R., Lloyd, J., Pettigrew, A., & Faragher, R. (2023). Myths about Down Syndrome. Brisbane, Australia: The University of Queensland. https://omny.fm/shows/living-with-down-syndrome-advice-from-gen-zs/myths-about-down-syndrome

5. Creating Out Loud: Easy Read Version

Project Lead
Dr Kate Power

"Creating Out Loud" is a peer coaching program designed with and for Australia's arts sector led by Dr Kate Power from The University of Queensland's School of Business. The program comprises a suite of Discussion Guides that address key issues affecting arts workers and provide a structure within which participants can discuss their own questions, challenges, and ideas.

Artistic practice affords people with intellectual disabilities the opportunities both to challenge stereotyping and exclusion, and to engage in paid work. Yet, arts work is precarious and artists with disabilities often experience exclusion and paternalism.

In this project, to develop the Easy Read materials, we undertook a research collaboration involving a small team of adults with Down syndrome, and other researchers from the DSRP and the UQ Business school. "Easy Read" documents are often created to make information accessible. To this end, they combine simplified language, content and layout with relevant images to support readers' comprehension of the text.

The Easy Read materials are now complete and the process of testing and refining them is underway.

Greater understanding is needed of best-practice professional development pathways for artists with intellectual disability and the communicative practices that might support those pathways. Through these materials, we hope that artists with intellectual disability can be supported in their work.

More information about the Creating Out Loud program is available here: **creatingoutloud.business.uq.edu.au**

Selected Output

Power, K., Faragher, R., & Lloyd, J. (2024). "Easy Read" peer coaching: Supporting inclusion for artists who have intellectual disability and/or low literacy. iMean7 19-21 June 2024, Bristol, UK.

6. Ethical, Legal and Social Dialogue around Genomics and Disability

Project Lead
Professor Karen Nankervis

Professor Karen Nankervis and Professor Rhonda Faragher have recently finalised a research project that involved leading a team of researchers from UQ and collaborating with partners in the disability sector to articulate the ethical, social and legal issues for people with disabilities and their families and implement a collaborative, co-design model to inform the design and conduct of human genetic research as well as genomics policy, research, education and practices.

In this research, we partnered with Down Syndrome Australia, the Queensland Genomics Health Alliance, the Queensland Disability Network and VALID, based in Victoria. Our research team comprised: Professor Robyn Gillies (School of Education), Professor Annemaree Carroll (Faculty of Humanities, Arts and Social Sciences), Dr Aideen Mcinerney-Leo (NHMRC Early Career Fellow), Professor Tamara Walsh (T.C. Beirne School of Law), Associate Professor Fran Boyle (Institute of Social Science Research) and Professor Simon Smith (Institute of Social Science Research).

This project received significant funding from the Commonwealth Government's Medical Research Future Fund to investigate an important area of interest to people with Down syndrome, their families and supporters. Scientific and medical developments in genomics are rapidly advancing with potentially profound impacts at an individual and societal level. For individuals with disability, advances in genomics can fundamentally alter their understanding of their condition, their self-identity and the existence of other individuals with the same condition. When scientific advances have existential impacts, it is imperative that affected individuals be centrally involved in decision making about the future direction of genomics and the possible medical, ethical and social implications for them. Conversely, scientists, clinicians and policy makers may not be included in the discussions people with disabilities are having about the impact of genomics on their lives. What is needed is a shared understanding and dialogue to bring together these critical perspectives to this issue.

In this project, we worked closely with people with disabilities, including Down syndrome, as co-researchers as well as participants in this research.

More information about the project is available here:
hass.uq.edu.au/research/we-need-to-talk

On the website, the Resources page has information from the study available in Easy Read format as well as videos developed to convey accessible information on genomics.

Selected Outputs

Vassos, M., Faragher, R., Nankervis, K., Breedt, R., Boyle, F., Smith, S., & Kelly, J. (2023). The ethical, legal, and social implications of genomics and disability: Findings from a scoping review and their human rights implications. Advances in Neurodevelopmental Disorders. https://doi.org/10.1007/s41252-023-00362-1

Yanes, T., Vaishnavi, N., Wallingford, C., Faragher, R., Nankervis, K., Jacobs, C., Vassos, M., Boyle, F., Carroll, A., Smith, S., & McInerney-Leo, A. (2023). Australasian genetic counselors' attitudes toward disability and prenatal testing: Findings from a cross-sectional survey. Journal of Genetic Counseling, 1-12. https://doi.org/http://doi.org/10.1002/jgc4.1788

7. Research into Sleep in Children with Down syndrome

Project Lead
Associate Professor Jasneek Chawla

The Kids Sleep Research Group at Child Health Research Centre, UQ, led by Associate Professor Jasneek Chawla, has continued to focus on improving aspects of diagnosis and management of sleep problems in children with Down syndrome.

Poor sleep is recognised to have a negative impact on health and wellbeing of not only children with Down syndrome but also their caregivers and families. As sleep problems are highly prevalent in this group of children, modifying sleep is essential to prioritise.

In the past six years A/professor Chawla's group has conducted a significant body of research in this area, contributing over 30% of publications in the field of Sleep and Down syndrome. This includes 4 of the 10 most cited papers including work describing the first Australian prevalence data, large cohort data describing the course of OSA in children with Down syndrome, a literature review identifying evidence gaps relating to residual OSA in children with Down syndrome, a paper on managing persisting OSA in this population of children and one of the first longitudinal studies to evaluate the impact of treatment of sleep on outcomes in children with Down syndrome. Collectively this work has been cited over 30 times with most publications being in the past 3 years. Findings have benefitted clinicians in informing families of children with Down syndrome in sleep clinics and have been shared with interdisciplinary colleagues at national forums (Australian Society of Otolaryngology Head & Neck Surgery Annual Congress 2023, Garnet Passe Frontiers Conference 2023 and Australasian Sleep Association, Sleep Down Under Annual Congress 2022-2023).

A/Professor Chawla has also been invited to speak at multiple community and professional forums locally, nationally and overseas.

Key studies of impact have included qualitative work describing the experiences of families who care for a child with Down syndrome that has sleep problems and an innovative study evaluating the potential of a novel sleep mat to provide non-invasive home diagnostic evaluation for sleep disordered breathing in children with Down syndrome. This work was featured in Research Australia's INSPIRE magazine in 2023.

Finally, in collaboration with Down Syndrome Queensland this group has undertaken a significant piece of work to assess health professionals' experiences of undertaking prenatal diagnosis discussions with findings published in a recent report to provide insights for future policy change.

Selected Outputs

Peer Reviewed Publications

J Chawla, A Bernard, S Staton, S Burgess, H Heussler. Longitudinal change in Sleep, Functional and Behavioural Characteristics in a Cohort of Children with Down syndrome. J Sleep Research 2023 http://doi.org/10.1111/jsr.14093

E Cooke, C Smith, MC Miguel, S Staton, K Thorpe, J Chawla. Siblings' Experiences of Sleep Disruption in Families with a Child with Down Syndrome. Sleep Health 2023 https://doi.org/10.1016/j.sleh.2023.10.002

A Collaro, K Sclip, W Pinzon Pérez, J Chawla. Contactless Sleep Monitoring using the Sonomat in Children with Down syndrome. Sleep Medicine 2023 https://doi.org/10.1016/j.sleep.2023.06.028

SL Tanner, A Collaro, J Chawla. The Management of Residual OSA Post Adentonsillectomy in Children with Down syndrome: the experience of a large tertiary sleep service Sleep Medicine 2023 https://doi.org/10.1016/j.sleep.2023.06.009

J Chawla, E Cooke, MC Miguel, S Burgess, S Staton. Parents' Experiences of Having a Child with Down syndrome and Sleep Difficulties. Behavioural Sleep Med 2023; 21(5): 570-584

E Cooke, L Coles, S Staton, K Thorpe, J Chawla. Communicating the Complex Lives of Families that Include a Child with Down syndrome. Health Sociology Review 2022 https://doi.org/10.1080/14461242.2022.2161405

M Ravutha Gounden & J Chawla. Management of Residual OSA post adentonsillectomy in children with Down syndrome: A systematic review. Int. J of Pediatric Otorhinolaryngology 2022; https://doi.org/10.1016/j.ijporl.2021.110966

J Chawla, A Bernard, H Heussler, S Burgess. Sleep, Function, Behaviour and Cognition in a Cohort of Children with Down Syndrome. Brain Sciences 2021 https://doi.org/10.3390/brainsci11101317

J Chawla, A Howard, S Burgess & H Heussler. Sleep problems in Australian children with Down syndrome: the need for greater awareness. Sleep Med 2021; 78: 81-87.

J Chawla, S Burgess & H Heussler. The Impact of Sleep Problems on Functional and Cognitive Outcomes in Children with Down Syndrome: A Review of the Literature. J Clin Sleep Med 2020; 16(10): 1785-1795.

Book Chapter

L Coles, E Cooke & J Chawla Confronting Meanings of Motherhood in Neoliberal Australia: Six Crystallized Case Studies (Book Chapter) Title: Biographical Research and the Meanings of Mothering: Life Choices, Identities and Methods; Editors: Dr Lisa Moran, Dr Katerina Sidiropulu-Janku; Publisher: Bristol University Press 2023.

8. Using Organoids to Investigate Genomics and Down syndrome

Project Lead
Professor Ernst Wolvetang

The extra chromosome 21 copy in Down syndrome affects the development, function and ageing of almost every organ system but contains only 235 of the approximately 25 000 protein coding genes present in the human genome.

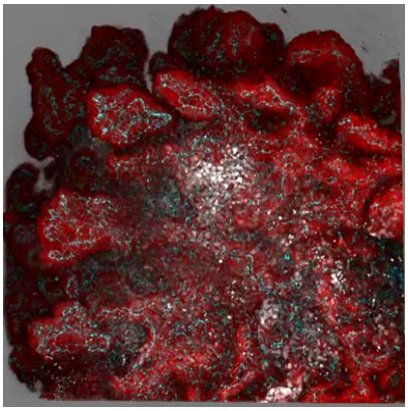
It was therefore initially thought that understanding the relationships between extra genes and disease in Down syndrome could be readily solved with human stem cell based functional genomics approaches (in which individual or multiple copies of the supernumerary genes are deleted in Down syndrome stem cells). However, with the advent of single cell analysis and the creation of increasingly complex organ mimics (organoids) from human Down syndrome stem cells, it has rapidly become clear that the extra copies of chromosome 21 genes deregulate the activity of genes on other chromosomes in complex ways, and that different subsets of chromosome 21 genes are over-expressed at different times of life.

While this makes researching Down syndrome more challenging, these advances in stem cell biology have also increasingly enabled the discovery and testing of novel therapeutics in an ethical and safe fashion. It remains imperative that throughout this process people with Down syndrome have an understanding of, as well as input in, the development of novel therapeutics that are aimed at improving their quality of life, as carried out by the Down syndrome Research Program at The University of Queensland.

Selected Outputs

Peng, L., Baradar, A. A., Aguado, J., & Wolvetang, E. (2023). Cellular senescence and premature aging in Down Syndrome. Mechanisms of Ageing and Development, 212, 111824–111824. https://doi.org/10.1016/j.mad.2023.111824

Shaker, M. R., Slonchak, A., Al-mhanawi, B., Morrison, S. D., Sng, J. D. J., Cooper-White, J., Khromykh, A. A., & Wolvetang, E. J. (2024). Choroid plexus defects in Down syndrome brain organoids enhance neurotropism of SARS-CoV-2. Science Advances, 10(23), eadj4735. https://doi.org/10.1126/sciadv.adj4735



Down syndrome Choroid plexus brain organoid that was used to elucidate why the Down syndrome brain is more susceptible to SARS-COV2 and to identify effective therapeutics.

Higher Degree by Research projects

Throughout the life of the Down Syndrome Research Program, research training has been an important component. Four projects are currently underway, each exploring aspects of intellectual disabilities, including from the perspective of people with disabilities themselves.

Ms Michelle Black

Characteristics of neuro-biophysiological and behaviour variations among children and adolescents with Down Syndrome.

Advisors:
Dr Susannah Tye (Principal),
Prof Rhonda Faragher

This research project aims to explore the neuro-biophysiological characteristics and behaviour variations among children and adolescents with Down Syndrome. This research project intends to assess neuro-biophysiological characteristics with a focus on understanding neuro-biophysiological markers of Heart Rate Variation (HRV) and related markers of inflammation, oxidative stress/HPA Axis, and Vagal tone. In addition, this research aims to explore the correlation between neuro-biophysiological characteristics and moderation of functional behaviour variations targeting emotion regulation, and other behaviours that may be moderated as a result of emotion regulation such as impulsivity, attention, learning and sleep in children and adolescents with Down syndrome.

Ms Radostina Breedt

Understanding the Role of People with Disabilities in Genomics Research: Developing a Model of Disability Engagement.

Advisors:
Prof Karen Nankervis (Principal), Prof Rhonda Faragher, Dr Maria Vassos

Community engagement in genomics research is recognised as a global priority to ensure ethical, equitable, and sustainable integration of genomics into health systems. The purpose of this study is to understand how genomics researchers perceive the role of people with disabilities and parents in genomics research, how they define meaningful disability engagement, and what are the barriers and facilitators of such engagement. This research project uses a mixed-method exploratory design beginning with a survey and semi-structured individual interviews with genomics researchers, followed by focused groups with people with disabilities and parents. The generated insights will inform the development of a model of disability engagement (MoDE) in genomics research.

Mr Ross Walker

Beyond the Performance: The Impact of Music Training for Children who have a Disability.

Advisors:
A/Prof Julie Ballantyne,
Prof Rhonda Faragher (Principal)

For some children, including many who have Down Syndrome, music is an essential part of who they are. In Queensland (Australia), legislation protects children's rights to receive a full education, including the opportunity to learn a musical instrument through their school, regardless of whether they have a disability.

Despite research demonstrating an array of benefits associated with learning musical instruments, children who have a disability appear to rarely become part of school instrumental music programs. This project investigated why, somewhere between government intent for Inclusion and recruitment, these children fall out of the picture.

Study with us!

If you are interested in undertaking a research project in the field of Down syndrome, we would welcome you to contact us. Students pursue higher degree research at the Honours, Masters and Doctoral level. Researchers also study with us at post-doctoral level and on sabbatical from other universities.

Possible research projects include the following. We also invite interested researchers to propose their own projects in the field.

TITLE	DESCRIPTION
Family Quality of Life (FQOL) and the experiences of Down syndrome	Previous studies in FQOL have produced a body of data that could be compared with a new cohort of families. We anticipate changes in the experiences of new parents due to changes in social factors and the impact of research leading to improvements in social inclusion.
Mathematical development of learners with Down syndrome	Assessment data from task-based interviews with primary aged children form the basis of analysis for developmental trends.
Friendships and social contacts	Friendships across the lifespan have positive outcomes in quality of life but what is the best way to build capacity?
Down syndrome and dyscalculia	Further understandings around the connection between Down syndrome and developmental dyscalculia will be explored in this project using techniques from a variety of fields such as developmental psychology, neuroscience or education.
Longitudinal study data analysis	Over the more than forty-five years of data collection for the longitudinal Down syndrome research project, a vast repository of developmental data has been acquired. Various research studies using these data sets could be developed.


Andy
Alex

The Longitudinal Down Syndrome Research Program

A story of research impact

The Down Syndrome Research Program (DSRP) is the world-renowned longitudinal study of individuals with Down Syndrome which commenced in 1977 and officially in 1978. Family of a baby born with Down syndrome in the greater Brisbane area were contacted for involvement in an initial study tracking their development. This longitudinal study, which has now spanned 46 years, is the longest, continuous study of its kind in the world, capturing the development of individuals with Down syndrome. Studies have investigated family interactions, child development, early intervention, mathematics development, inclusive education, quality of life, ageing and mental health.

The Michael Cameron Fund, established in 1985, and continuing to be supported by the Cameron family and others in the community, has been instrumental over the years in supporting research in the field of Down syndrome. The research has provided crucial outcomes for individuals with intellectual disabilities and their families. The impact of this research is far-reaching and speaks to the value of diversity, social inclusion, and societal awareness and acceptance.

Research in the program has followed the needs of participants and their families. In 1998, with the young adults in the longitudinal study reaching their 20s, a two-year literacy program for adults with intellectual disabilities was established – the award-winning Latch-ON program.

Research at the DSRP is also funded by external grants. Recent grants have enabled us to employ individuals with Down syndrome who have been trained to work as research assistants. This research was undertaken into the quality of life of young adults with Down syndrome. The team is planning to extend this work to investigate the quality of life of our older participants in the longitudinal cohort.

In 2018, the DSRP received the World Down Syndrome Day award from Down Syndrome International for outstanding contribution towards scientific advancement related to Down syndrome.

Below, Dr Anne Jobling reflects on the history of this important study.

A short history of a long study

The longitudinal study into Down syndrome forms the bedrock of the DSRP at UQ. In 2017, the Chancellor of the University, Mr Peter Varghese AO, paid tribute to the longitudinal study. His speech is available here: **about.uq.edu.au/chancellor/speeches-and-articles/michael-cameron-fund-31-years-supporting-down-syndrome-research**

Here, Dr Anne Jobling, one of the long-standing researchers and former Director of the DSRP, gives an account of the longitudinal study to this point.

The Fred and Eleanor Schonell Special Education Research Centre evolved from the Remedial Education Centre which was established by Sir Fred Schonell in 1958 to conduct research into issues related to disability. The Down Syndrome Research Program was established by Pat Gunn, Robert Andrews and Paul Berry in 1977 and was hosted by the Schonell Centre for over 40 years.

The original research was established to investigate the interactions that occurred between mothers and their infants with Down syndrome, and from this study the initial longitudinal investigation of the development of children with Down syndrome began. The study of the development of persons with Down syndrome has been at the core of the research program with the aim of following a group of children with Down syndrome through their early years using an intensive data collection protocol. This continued as the children aged and progressed through infancy into childhood adolescence and adulthood.

Many other associated studies have been carried out over time. Studies related to family life, teaching and learning as well as general health and well-being, and these continued to engage with original cohort families and their children.

The longitudinal study began with seed funding from the National Health and Medical Research Council. Further funding came from the Australian Research Council, APEX and Perceptual Trustees Fund. We especially appreciate the help of the Michael Cameron Fund established by Mary Gavin, an aunt of one of the first children in our research program, and her family. Within the Schonell Centre, The School of Education colleagues also provided the program with a great deal of support.

We pay special tribute to the DSRP participants, the more than 200 families and their children, without whom this research would not have taken place. Their faithfulness to the research has been outstanding along with the support of the Michael Cameron Fund

Historical context of the research

The original study sample consisted of three cohorts of Brisbane born infants and children with Down syndrome (living in their family home) and their families.

The three cohorts of participants were described by Monica Cuskelly and colleagues[2] in a research report from 2016 (p. 113):

Various studies have contributed to the creation of this unique longitudinal database of individuals with DS over their life course. The database (full sample) comprises three groups based on the research project from which they originated: a longitudinal population group born in Brisbane between 1973 and 1978 (Group 1; n = 72), a longitudinal group either not born in Brisbane or born after 1978 (Group 2; n = 66), and a group comprising participants who were involved in shorter studies within the program and who continued to contribute assessment data after completion of the specific project for which they were originally recruited (Group 3; n = 67).

2 Cuskelly, M., Povey, J., & Jobling, A. (2016). Trajectories of Development of Receptive Vocabulary in Individuals with Down Syndrome. Journal of Policy and Practice in Intellectual Disabilities, 13(2), 111–119. https://doi.org/10.1111/jppi.12151

Early data collection

Those children who were born late 1977, 1978 to early 1979 were assessed six monthly using Bayley Scales of Development: (Mental, Motor and Behavioural) until they were 2 to 3 years of age. An interview with the mother (usually) was conducted as well as an assessment, and infant and toddler temperament data were also collected. Later middle childhood and teacher temperament data were also collected during their yearly visits to the Schonell Centre or during home visits when necessary.

As the children aged, the Stanford Binet (3) and (4) were used as well as the Hiskey Nebraska to track cognitive development while the Reynell Scales followed language and Bruininks Test of Gross Motor Skills assessment tasks followed motor development.

Areas of research focus

Studies in four main areas were undertaken over the years.

1. Cognitive Development

Principal researchers: Berry, Gunn, Cuskelly, Crombie, Gilmore.

Data Sources: Bayley Scales; Laboratory sessions – interview, play and looking at books; Peabody Picture Vocabulary Test; Hiskey Nebraska; Lock Box; Stanford Binet.

Outcomes

- Wide within group variability.
- No evidence of final plateau. (At the time, it was thought that intellectual development of individuals with Down syndrome plateaued in late adolescence.)
- Necessity to examine the efficacy of the entire educational experience offered to children with Down syndrome rather than assuming a few intensive years early in life will make a substantial difference. Early intervention programs need to investigate social disadvantage and biological impairment in combination with programs.
- Lack of appropriate school programs and opportunities for lifelong learning needed to be developed.
- Receptive language seems to decline after formal schooling ended.

2. Language and literacy

Principal researchers: Andrew, Berry, Gunn, Cuskelly, Jobling, Moni, Lloyd, Morgan, Farrell.

Data Sources: Laboratory sessions - looking at books; Peabody Picture Vocabulary Test; Reynell Scale; Neale Analysis of Reading; Burt Word Test.

Outcomes

- Pre-linguistic communication:
  - mother preferred to the environment or toys
  - quality was interpersonal; ratherthan referential.
- Importance of early reading and looking at books with family members.
- Literacy skills developed during school years was de-valued in adolescence and adult years.
- Trajectory of receptive language development was established.
- Latch-On program was developed leading to evidence-based data of student progress from Australia, Canada & Ireland.

3. Family life and temperament

Principal researchers: Berry, Gunn, Cuskelly, Hayes, Gilmore.

Data Sources: Bayley Infant Behaviour Scale; Temperament questionnaires to parents: Infant, Toddler & Middle Childhood as well as to teachers in middle childhood. Various scales including Adaptative Behaviour (ABAS); Moos Family Environment Scale; AIR; as well as siblings and their family life investigations.

Outcomes

- No age or gender differences in temperament between pre-schoolers and adolescents.
- No average or particular temperament characteristics: a variety of temperaments were evident with wide variations.
- Siblings: perception was not tenable that the child with Down syndrome is disruptive of family functioning.
- Importance of self-regulatory skills and mastery motivation
- For families: same concerns as for typically developing children.
- Sibling relationships similar, but some disruption to the normative pattern of life stages; for some, there could be a decade of involvement beyond typical parenting years.

4. Motor development and well-being

Principal researchers: Gunn, Berry, Jobling, Virij-Babul, Cuskelly; Rutherford.

Data Sources: Bayley Infant Motor Scales; Bruininks Motor Skills 10 to 16 years, The Henderson Revision of the Test of Motor Impairment; Health knowledge and behaviour questionnaires, tasks and projects.

Outcomes

- A general slower rate of developmental progress to achieve early motor milestones.
- Variable gross and fine motor skill development in the school years with particular difficulties in the areas of balance and motor responses as well as with some fine motor skills.
- Limited knowledge and understanding of how to maintain health and well-being – particularly the role of regular exercise and diet.

Continuing research initiatives

Our research continues and projects are described elsewhere in this report. Our work on mental health has produced variable results indicating a need to understand the trajectory of mental health difficulties and environments that support individuals. As our first cohort participants age, we intend to continue our journey with them, sharing what we learn to enhance the quality of life of older adults with Down syndrome around the world.

Publications

The Down Syndrome Research Program has over 200 publications since the 1970s. The full list is available on our website and full texts are available through the UQ library eSpace collection. Over the years, the fields of study have changed as new areas of research need have arisen in the field of Down syndrome. In many cases, the research teams responded to emerging needs of the longitudinal study participants.

Below, we list publications since 2020.

2020

Chawla, J., Burgess, S., & Heussler, H. (2020). The Impact of Sleep Problems on Functional and Cognitive Outcomes in Children with Down Syndrome: A Review of the Literature. J Clin Sleep Med; 16(10): 1785-1795.

Cuskelly, M. (2020). Siblings' influence on the development of individuals with Down syndrome. In J.A. Burack, J.O. Edgin, L. Abbeduto & J. Busciglio (Eds.), The Oxford Handbook of Down Syndrome and Development, Oxford UK: Oxford University Press.

Cuskelly, M., Moni, K., McMahon, M., Jobling, A., Lloyd, J., & Leggatt-Cook, C. (2020). Futures of adults with intellectual disability: Staff expectations. Journal of Intellectual & Developmental Disability, 1-10. https://doi.org/10.3109/13668250.2020.1814490

Faragher, R., Robertson, P., & Bird, G. (2020). International guidelines for the education of learners with Down syndrome. Down Syndrome International (DSi). https://www.ds-int.org/Handlers/Download.ashx?IDMF=7a4a9546-287d-49c1-8573-888319d7310f

Faragher, R., & Clarke, B. (2020). Inclusive practices in the teaching of mathematics: Some findings from research including children with Down syndrome. Mathematics Education Research Journal, 32(1), 121-146. https://doi.org/10.1007/s13394-019-00294-x

Lloyd, J., Moni, K., Cuskelly, M., & Jobling, A. (2020). Exploring the complexity of implementing National Disability Insurance Scheme plans for adults with intellectual disability: Parents' perspectives. Journal of Intellectual & Developmental Disability, 1-10. https://doi.org/10.3109/13668250.2020.1843764

McMahon, M., Moni, K., Cuskelly, M., Lloyd, J., & Jobling, A. (2020). Aspirations held by young adults with intellectual disabilities and their mothers. Australian Journal of Career Development, 29(2), 107-116. https://doi.org/10.1177%2F1038416220916813

2021

Chawla, J., Bernard, A., Heussler, H., & Burgess, S. (2021). Sleep, Function, Behaviour and Cognition in a Cohort of Children with Down Syndrome. Brain Sciences 2021 https://doi.org/10.3390/brainsci11101317

Chawla, J., Howard, A., Burgess S, & Heussler, H. (2021). Sleep problems in Australian children with Down syndrome: the need for greater awareness. Sleep Med; 78: 81-87.

Faragher, R., Chen, M., Miranda, L., Poon, K., Rumiati, Chang, F.-R., & Chen, H. (2021). Inclusive education in Asia: Insights from some country case studies. Journal of Policy and Practice in Intellectual Disabilities, 18(1), 23-35. https://doi.org/10.1111/jppi.12369

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2022

Cooke, E., Coles, L., Staton, S., Thorpe, K., & Chawla, J. (2022). Communicating the Complex Lives of Families that Include a Child with Down syndrome. Health Sociology Review https://doi.org/10.1080/14461242.2022.2161405

Lloyd, J., Moni, K., Cuskelly, M., & Jobling, A. (2022). The National Disability Insurance Scheme: voices of adults with intellectual disabilities. Research and Practice in Intellectual and Developmental Disabilities, 9(1), 5-13. https://doi.org/10.1080/23297018.2021.2004382

Ravutha Gounden, M. & Chawla, J. (2022). Management of Residual OSA post adenotonsillectomy in children with Down syndrome: A systematic review. International Journal of Pediatric Otorhinolaryngology. https://doi.org/10.1016/j.ijporl.2021.110966

Wanjagua, R., Hepburn, S. J., Faragher, R., John, S. T., Gayathri, K., Gitonga, M., ... & Sindano, D. (2022). Key learnings from COVID-19 to sustain quality of life for families of individuals with IDD. Journal of Policy and Practice in Intellectual Disabilities, 19(1), 72-85. https://doi.org/10.1111/jppi.12415

2023

Chawla, J., Cooke, E., Miguel, MC., Burgess, S., & Staton, S. (2023). Parents' Experiences of Having a Child with Down syndrome and Sleep Difficulties. Behavioural Sleep Med; 21(5): 570-584

Chawla, J., Bernard, A., Staton, S., Burgess, & Heussler, H. (2023). Longitudinal change in Sleep, Functional and Behavioural Characteristics in a Cohort of Children with Down syndrome. Journal of Sleep Research 2023;e14093 http://doi.org/10.1111/jsr.14093

Coles, L., Cooke, E., & Chawla, J. (2023). Confronting Meanings of Motherhood in Neoliberal Australia: Six Crystallized Case Studies (Book Chapter) In L. Moran, K. Sidiropulu-Janku (Eds.) Biographical Research and the Meanings of Mothering: Life Choices, Identities and Methods. Bristol University Press.

Collaro, A., Sclip, K., Pinzon Pérez, W., & Chawla, J. (2023). Contactless Sleep Monitoring using the Sonomat in Children with Down syndrome. Sleep Medicine https://doi.org/10.1016/j.sleep.2023.06.028

Cooke, E., Smith, C., Miguel, MC., Staton, S., Thorpe, K., & Chawla, J. (2023). Siblings' Experiences of Sleep Disruption in Families with a Child with Down Syndrome. Sleep Health https://doi.org/10.1016/j.sleh.2023.10.002

Faragher, R. M. (2023). Individual student characteristics, abilities and personal qualities and the teacher's role in improving mathematics learning outcomes. In A. Manizade, N. Buchholtz, & K. Beswick (Eds.), The evolution of research on teaching mathematics. International perspectives in the digital era. (pp. 227-253). Springer Nature. https://doi.org/https://link.springer.com/book/10.1007/978-3-031-31193-2

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Faragher, R., Lloyd, J., Pettigrew, A., & Faragher, R. (2023). How to communicate with people with Down Syndrome. Brisbane, Australia: The University of Queensland. https://omny.fm/shows/living-with-down-syndrome-advice-from-gen-zs/how-to-communicate-with-people-with-down-syndrome

Faragher, R., Lloyd, J., Pettigrew, A., & Faragher, R. (2023). Myths about Down Syndrome. Brisbane, Australia: The University of Queensland. https://omny.fm/shows/living-with-down-syndrome-advice-from-gen-zs/myths-about-down-syndrome

Peng, L., Baradar, A., Aguado, J., & Wolvetang, E. (2023). Cellular senescence and premature aging in Down Syndrome. Mechanisms of Ageing and Development, 212, 111824–111824. https://doi.org/10.1016/j.mad.2023.111824

Tanner, SL., Collaro, A., & Chawla, J. (2023). The Management of Residual OSA Post Adentonsillectomy in Children with Down syndrome: the experience of a large tertiary sleep service Sleep Medicine https://doi.org/10.1016/j.sleep.2023.06.009

Vassos, M., Faragher, R., Nankervis, K., Breedt, R., Boyle, F., Smith, S., & Kelly, J. (2023). The ethical, legal, and social implications of genomics and disability: Findings from a scoping review and their human rights implications. Advances in Neurodevelopmental Disorders. https://doi.org/10.1007/s41252-023-00362-1

Yanes, T., Vaishnavi, N., Wallingford, C., Faragher, R., Nankervis, K., Jacobs, C., Vassos, M., Boyle, F., Carroll, A., Smith, S., & McInerney-Leo, A. (2023). Australasian genetic counselors' attitudes toward disability and prenatal testing: Findings from a cross-sectional survey. Journal of Genetic Counseling, 1-12. https://doi.org/http://doi.org/10.1002/jgc4.1788

2024 to date

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

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Give to the Michael Cameron Fund

Many of us take for granted the simple gifts given to us at birth – a safe and healthy start to life, access to a quality education, family and friends, meaningful work and living circumstances.

For people with Down syndrome, these basic needs can be challenging to reach. Families are impacted by tests to their health and wellbeing, ranging from sleep disorders that can affect a child's cognitive ability, through to a child or adult's understanding of mathematics.

The University of Queensland Down Syndrome Research Program has transformed the lives of people with Down syndrome. Since its inception in 1978 the DSRP has continued to discover, innovate and ultimately support families to live a better life – one where they are not limited by having Down Syndrome, but can flourish and thrive, just as any parent would wish for their child.

Philanthropy has been essential to sustain this program. The Down Syndrome Research Program has been generously supported by the Michael Cameron Fund, established in 1985 by the family of Michael Cameron, who passed away at age seven, after being recruited at birth for the program.

Since then, the longitudinal study has collected data about cognitive development, motor development, and analysed the impact on parents and siblings on having a child with Down syndrome in the family. It has dispelled a number of myths about Down syndrome, and it has provided an opportunity for families with a member with Down Syndrome to connect and socialise with other families in similar situations.

Without a doubt, the research enabled through the Michael Cameron Fund has led to significant improvements in the lives of people with Down syndrome across the world, and babies born today with Down syndrome can look forward to dramatically different lives from those first participants in the longitudinal cohort.

The DSRP can only sustain its research with continued support from the community.

Please consider a donation towards the Michael Cameron Fund, to continue supporting the Down Syndrome Research Program and creating change for families.

We also welcome conversations with interested donors about the Down Syndrome Research Program. If you would like further information about particular areas of research or the social benefits of the program, please contact the Faculty's Advancement team who would be happy to work with you towards a gift that is meaningful to you.

How to donate to the Down Syndrome Research Project at UQ

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If you have enquiries about your gift, or would like more information on how to give, please contact **advancement@hass.uq.edu.au.**

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