

A Changed World:

Supporting the Down Syndrome
Research Program (DSRP)





The Down Syndrome Research Program (DSRP)

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 comfortable living circumstances. Yet for people living with Down syndrome, in the past these most basic needs have been difficult to reach.

Thanks in part to ground breaking research at UQ, individuals born today with Down syndrome can look forward to happy and productive lives. Such improved quality of life and opportunities for social inclusion have meant many individuals are now engaging in previously unattainable situations such as inclusive workplaces, adult community activities, independent living arrangements and the social aspects of adulthood.

However, there remain significant barriers to fulfilling the promise of inclusivity. Many professional and social environments are still fraught with challenges due to the inexperience and lack of guidance from members of the community who may never have met a person with Down syndrome before. There is a great deal more work that needs to be done to achieve a fairer, more inclusive, Australian society.

Throughout its 42 years of longitudinal research, the Down Syndrome Research Program (DSRP) has transformed the lives of countless individuals with Down syndrome. As we approach the 50th anniversary of this original study, two new avenues of research present the opportunity to take further strides for future generations.



“There are two issues that may hinder further research: first, availability of research funding could be limited by the incorrect perception that Down syndrome has become a rare condition. The second is that some believe the important work on Down syndrome is complete.”

**Associate Professor
Rhonda Faragher**

Director
Down Syndrome Research Program
School of Education
The University of Queensland

Our Global Impact

In 1978, a team of visionary researchers at The University of Queensland embarked on a first-of-its-kind longitudinal study. They engaged the families of over 200 babies born with Down syndrome in the Greater Brisbane area. Up to that point, being born with Down syndrome usually meant a difficult and short life spent in institutions away from family with limited educational and social opportunities. Yet as families became empowered to reject institutional care, the DSRP set out to document these changes, tracking the impacts on the outcomes of the children and their families.

Since its launch, the study has collected data across the lifespan of our participants around cognitive development, motor development, mother-baby interactions, temperament, educational achievement and family functioning; as well as the impact these have had on family relationships.

Most notably, the program has dispelled misconceptions that an individual's cognitive development plateaus at the age of 12 and that children

with Down syndrome could never hope to read or write effectively. Broadening approaches in the classroom, one study investigated adult literacy development, eventually producing the award-winning Latch-on® literacy program for adults with intellectual disabilities; since adopted internationally in Canada and Ireland through licensing agreements. Institutionalisation is now largely a thing of the past and thanks to findings of the Down Syndrome Research Program (DSRP), individuals can experience fuller lives than ever before.

DSRP remains a world leader in the field of Down syndrome research by investigating and responding directly to issues raised by participants and their families, empowering countless lives around the world. That world has come a long way since 1978, and presents its own challenges. A new digital era has transformed the way individuals with Down syndrome interact, requiring a deeper understanding of the role of these tools in social inclusion and life-changing opportunities.



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Adapting to New Challenges

Today, more technologically adept generations of individuals with Down syndrome are entering adulthood, extending the social contexts in which interactions takes place. With more social environments available than ever before - ranging between personal finance in a cashless society, online networks, to recreation and employment situations - the world is now a vastly different place for individuals with Down syndrome. New environments have created new challenges.

However, these dramatic changes have not yet been documented, meaning myths of the past have given way to myths of the present. Further research is needed to understand this new adulthood, and will inform how the surrounding community can be more inclusive to support and encourage young adults, both in presenting new opportunities and minimising risks.

While the first longitudinal study responded to the specific literacy, numeracy and social needs of young individuals and their families, much of Australia still lacks an understanding of disability. Society is not always kind to those who are different and coupled with this newer digital world, stigma and social commentary can be easily shared.

Our Down Syndrome Research Program continues in its aim to undertake research focused on improving the quality of life for individuals with Down syndrome and all who share their lives.





Short and Long-Term Opportunities

Life can be good for people with Down syndrome. Early intervention programs, inclusive primary and secondary school education, along with improvements in health care, have led to dramatic changes in the quality of life for individuals with Down syndrome. Educational and social inclusion throughout childhood can lead to an adulthood that is vastly different from before. As young adults move into contexts that have previously been closed to them, such as post-secondary education and open employment, supporting them in these contexts is the new frontier of Down syndrome research.

New Adulthood

Young adults with Down syndrome can have connected lives. Socialising with friends throughout school allows many to adopt similar lifestyles to their peers; whether that be using social media, generating web content or using assistive technology in the form of apps for finance, transport and scheduling.

Young Australian adults with Down syndrome are no longer totally reliant on carers and respite services. In documenting what life is really like for our recent school leavers, we can learn about the new adulthood for individuals with Down syndrome and overcome the unique obstacles they face.

The Next Generation

In 2028, the original longitudinal study will be 50 years old recognising that babies born with Down syndrome can expect a vastly different life to those who were born in 1978. Highlighting the profound importance of family and supportive environments, research remains integral to broadening societal attitudes in the classroom and beyond.

For a new generation and their families, tracking the development of babies born today will enable an exploration of how advances in health care, early intervention and education have transformed social contexts. By inviting the families of every newborn baby with Down syndrome in Australia to participate in a major population-based longitudinal study, this will be a unique project of global significance, answering a new digital era.

The 1978 cohort helped change the world. Now, a new world needs a new perspective.

Kirra's Story

Born in 2011 with a complex congenital heart defect, Kirra had her first heart surgery at just five weeks of age. This was followed by another corrective open-heart procedure at 10 months. Throughout this period the standard of care offered was no different from her peers.

Since recovering and attending day care from the age of one, Kirra has been in an inclusive setting alongside her peers. After attending specialised early intervention programs, including the Early Childhood Development Program at Mount Ommaney and

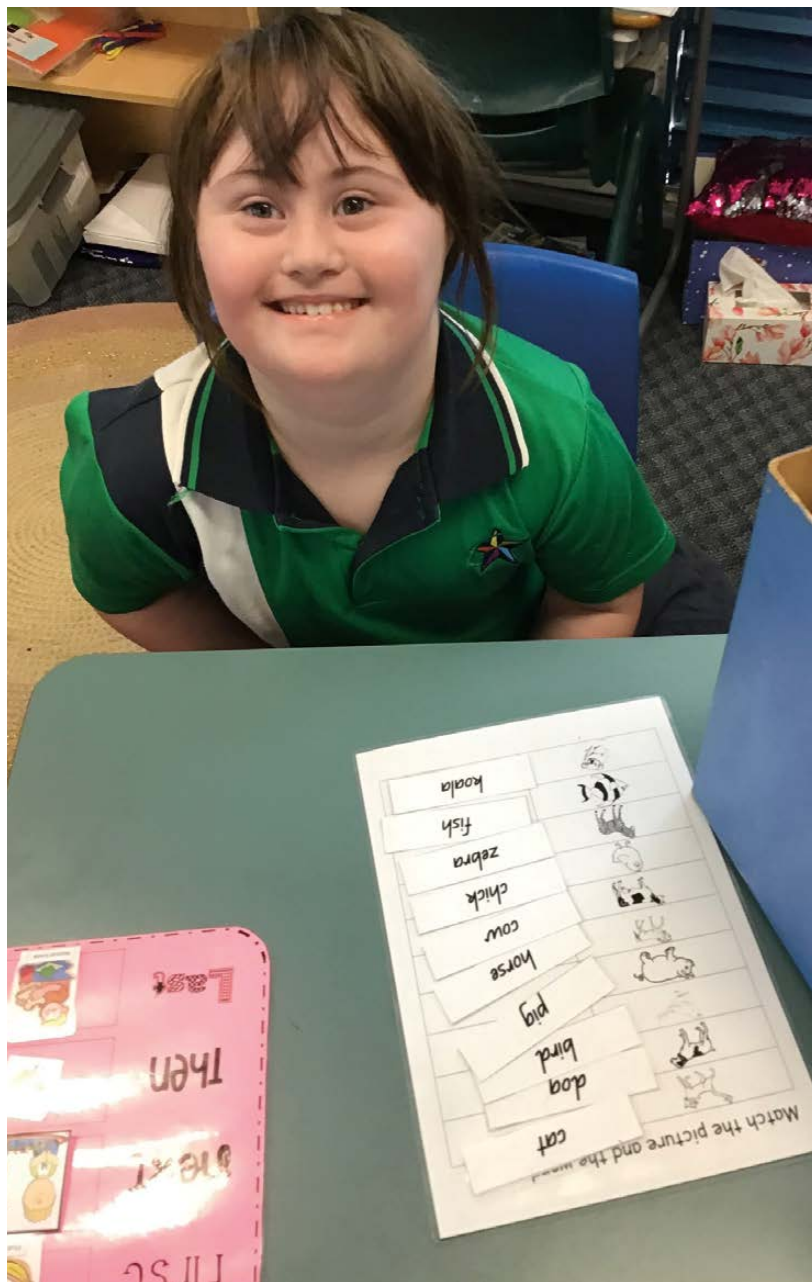
mainstream kindy at C&K, Australian law ensures that Kirra will always have the right to high quality, inclusive education.

Having engaged with a digital world since toddlerhood, during school she uses a range of play-based speech and language apps on her iPad. Entitled to receive necessary support and adjustments to experience success in her studies; Kirra can read and write and enjoys her classwork. Alongside her many friends, outside of school, Kirra enjoys ballet, drama and gymnastics.





Supporting the DSRP will ensure Kirra and her peers reach their full potential; as she overcomes unique challenges and grows into this new adulthood.



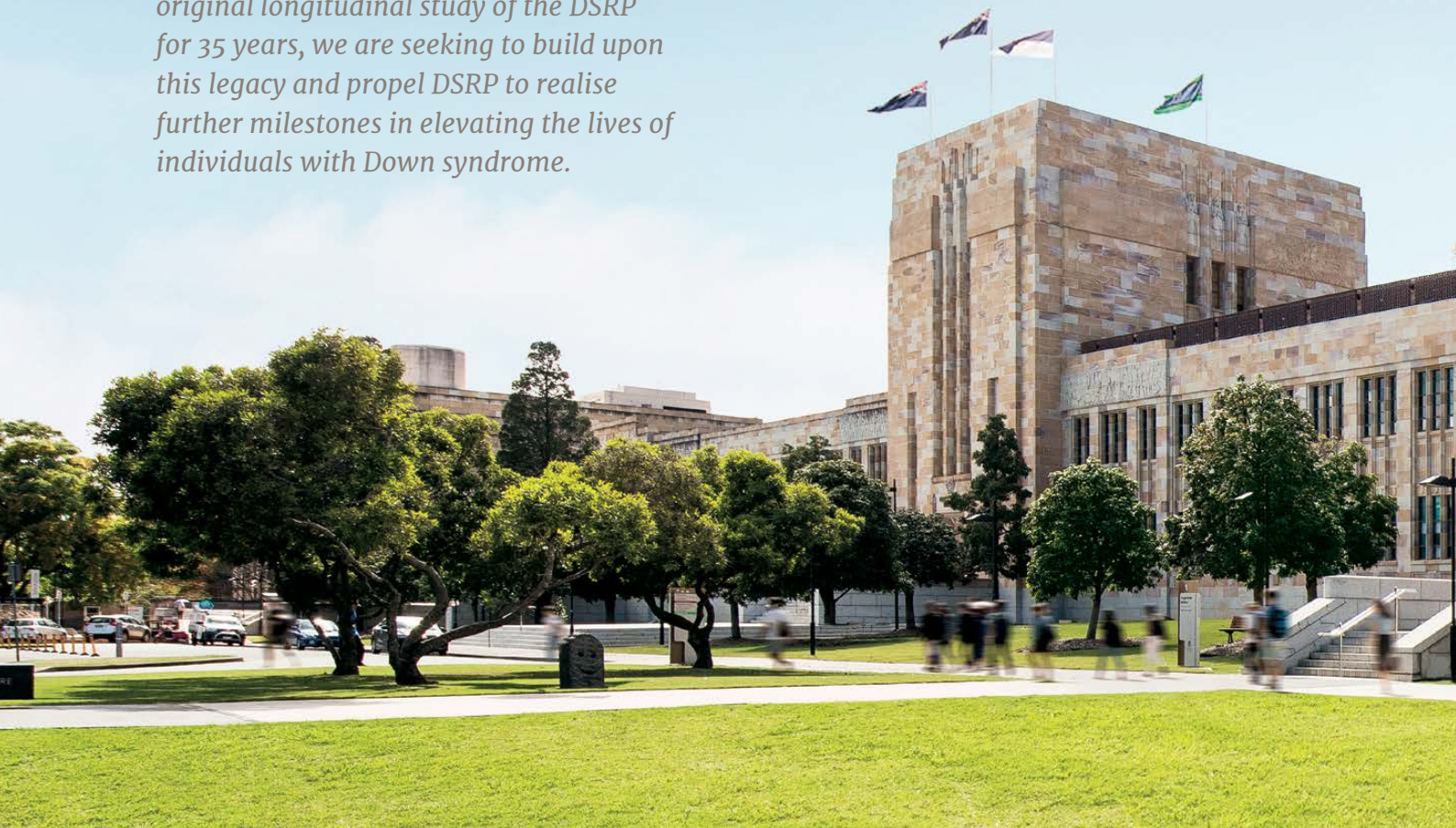
Michael Cameron's Legacy

In 1985, the Michael Cameron Fund was generously established by the Cameron family in memory of Michael, one of the original participants in the longitudinal study, who died at just seven years of age.

This philanthropy has been essential to sustain the DSRP when presented with gaps in research funding

or grants. It has also enabled families to participate, learning from each other and the research findings. On top of this, it has propelled research forward to dispel countless myths, improving the quality of life of those with Down syndrome and their families. This ongoing support of the Michael Cameron Fund has benefitted individuals with Down syndrome all over the world.

While this funding has supported the original longitudinal study of the DSRP for 35 years, we are seeking to build upon this legacy and propel DSRP to realise further milestones in elevating the lives of individuals with Down syndrome.



Why UQ

The University of Queensland's Down Syndrome Research Program (DSRP) transforms lives. Beginning with the original population study in 1978 as the oldest, most intact longitudinal study of Down syndrome in the world, research projects within the DSRP have expanded horizons for people with Down syndrome and their families in ways previously unimaginable.

Our long standing partnerships with Down Syndrome International, Down Syndrome Australia and Down Syndrome Queensland has meant that babies born today with Down syndrome can expect to live long

and fulfilling lives, moving into contexts previously unavailable to them.

Alongside UQ's standing as one of Australia's leading research and teaching institutions, the DSRP has forever enhanced the quality of life for families and individuals connected to Down syndrome. In 2018, the DSRP received the prestigious Scientific Research Award from Down Syndrome International in recognition of this enormous body of research; effectively improving understanding of Down syndrome across the world.



Thank you

We welcome conversations about supporting the next era in the DSRP's research as well as the social benefits of the program. Thank you for giving individuals with Down syndrome the chance to succeed through this life-changing research.

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