

A longitudinal program of  
research with families and their  
children with Down syndrome:  
Themes and Outcomes



# Acknowledgements

**Families:** a special tribute to all the 200 + families and their children without whom this research would not have happened. Their faithfulness has been outstanding.

**Researchers:** numerous but particularly - Robert Andrews, Paul Berry, Patricia Gunn, Alan Hayes, Monica Cuskelly, and various PhD students ....

**Australian and overseas colleagues:** numerous but particularly Brian Stratford, Jennifer Wishart, Sheila Glenn, Helgard Ruhl, Patricia Minnes ....

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# Historical background

Sample – home-reared and  
born in Brisbane

Early data collection schedule

A snapshot of program  
activities in 1987:

123 families with DS + 35 control.

119 visits to UQ

159 school visits

42 consultations

7 seminars

Expo display - 1988



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# Publications

From 1977 to present over 200 scholarly publications and book chapters.

Books: Burns & Gunn

Jobling & Virji-Babul

Stratford & Gunn

Cuskelly & Jobling

Faragher & Clarke

From 1977 to 2018 there have been more than 35 Senior Research Assistants.



**Literacy for  
children with  
Down syndrome:**

**Early days**

Margaret Farrell and Pat Gunn



Fred and Eleanor Schonell Special Education Research Centre

**ACTIVITIES FOR BABIES  
AND TODDLERS  
WITH DOWN SYNDROME:  
A PHYSIOTHERAPY APPROACH**  
Rose-Anne Kelso & Sue Price



Fred and Eleanor Schonell Special Education Research Centre  
University of Queensland



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# Family participation

## Cohort 1: n= 72

Born in Brisbane 1973-1979

Provided ongoing data

Emerging new trends in community and education settings

## Cohort 2: n= 66

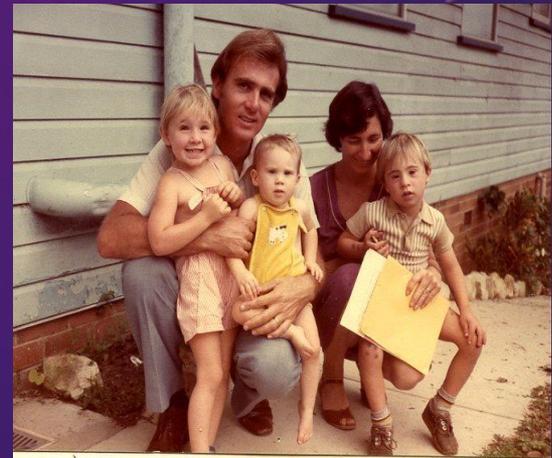
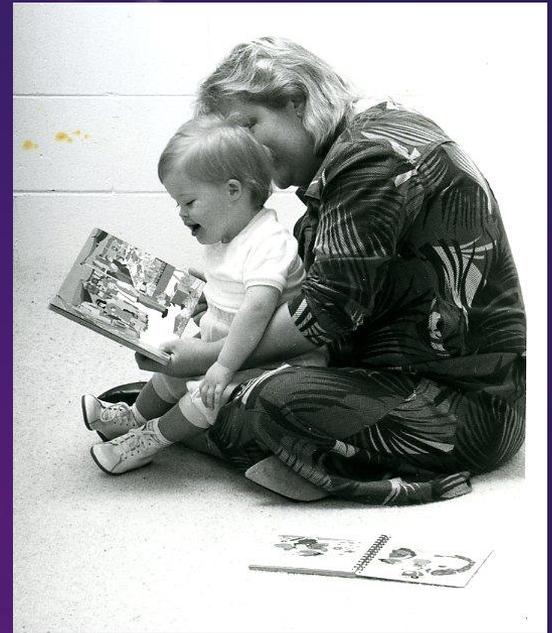
Not all born in Brisbane from 1978 to present

Provided ongoing data

New trends becoming established

## Cohort 3; n= 67

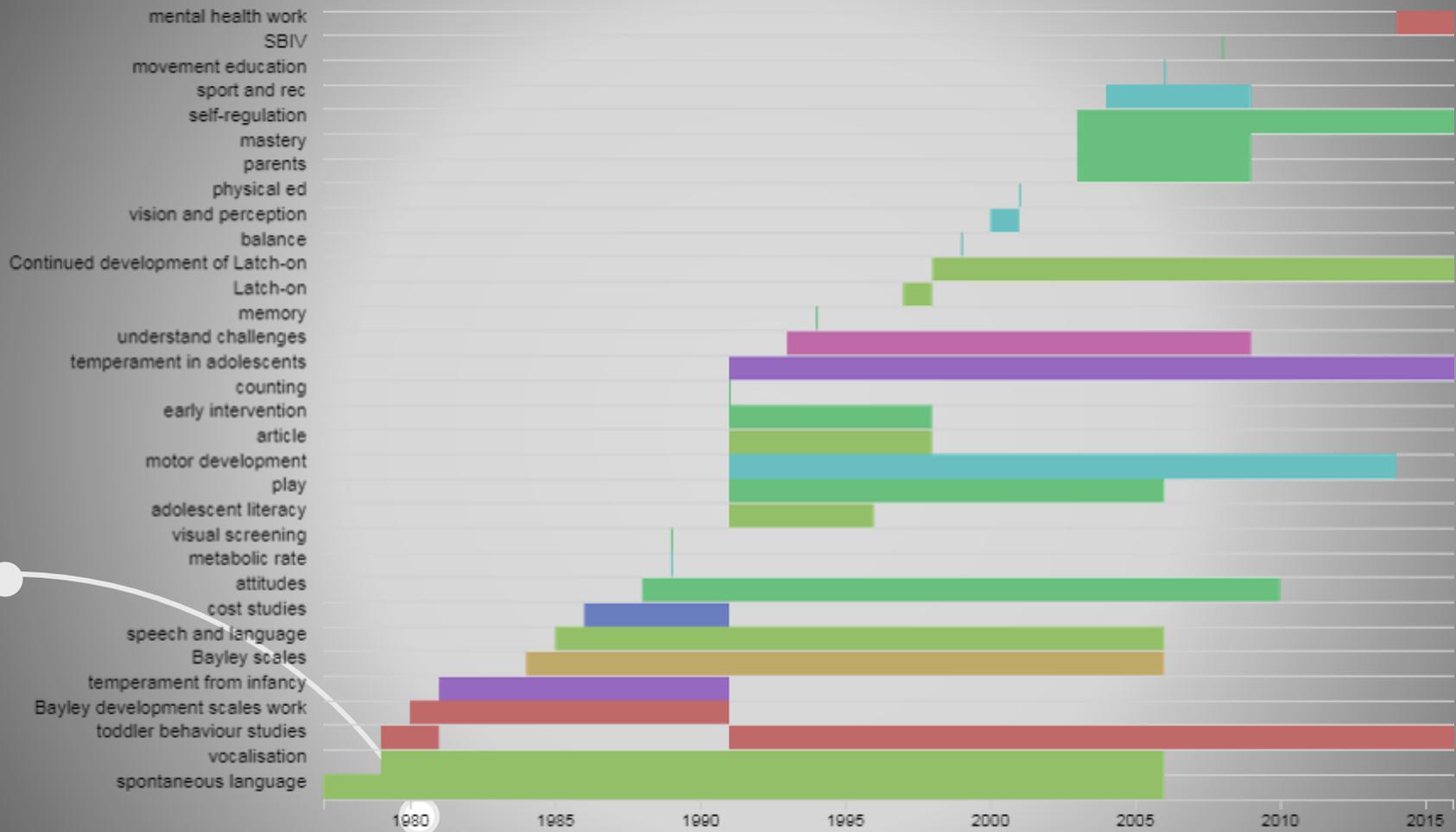
Made specific project contributions but some continued to contribute data after project completed.



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# Graph representation of research outputs



# Four major and interwoven themes

Cognitive development

Language and literacy

Families, temperament and behaviour

Motor development and well being

# Cognitive development

## Data sources

Bayley Mental Scales

Lab sessions – play and looking at books

Peabody Picture Vocabulary Test

Hiskey Nebraska

Lock Box

## Principal researchers

Paul Berry, Patricia Gunn, Mary Crombie, Linda Gilmore, Monica Cuskelly

# Outcomes

No evidence of final plateau in mental age

Wide within-group variability

Re- EIP: no group differences due to commencement, frequency or duration of attendance.

But need to investigate social disadvantage + biological impairments in combination with programs.

## Questions to be answered

Home life

EIP too general

Lack of appropriate school programming

Later development may show greater plasticity – ‘when slow may be fast enough’.

# Language and literacy

## Data sources

Mother baby – looking at books – videotaped lab sessions

Early Reading – small book

Receptive Language Score : PPVT – assessment

Post-School Program Development – Latch-On.

Peabody Picture Vocabulary Test

Neale Analysis of Reading

Burt Word Test

## Principal researchers:

Robert Andrews, Paul Berry, Patricia Gunn, Margaret Farrell, Monica Cuskelly, Karen Moni, Anne Jobling, Jan Lloyd.

# Outcomes

Pre-linguistic communication: looking at mother was preferred to environment and toys; quality was interpersonal rather than referential.

Importance of early reading and looking at books with mother/family members.

Literacy skills developed during school years de-valued in adolescence and totally ignored in adult years.

Trajectory of receptive language development.

Evidence of Latch-On students' progress in Australia, Canada and Ireland.



# Family life: temperament & behaviour

## Data Sources

Bayley Infant Behaviour Scale.

Temperament questionnaires to parents: infant, toddler & middle childhood as well as to teachers in middle childhood.

Various questionnaires including Adaptive Behaviour Siblings and their family life

## Principal researchers:

Paul Berry, Patricia Gunn, Monica Cuskelly, Alan Hayes

# Outcomes

No age or gender differences in temperament between preschoolers and adolescence.

No average or particular temperament characteristics: a variety of temperaments; wide variations

Siblings: perception that child with DS is disruptive of family functioning not tenable.

Importance of self-regulatory skills and motivation.

For families: same concerns; sibling relationship similar but disruption of normative pattern of life stages; some decade beyond normal parenting.

# Motor development & well-being

## Data Sources

Bayley Infant Motor Scales

Bruininks Motor Skills – 10 to 16 years

Health knowledge and behaviour projects/tasks

## Principal Researchers:

Patricia Gunn, Paul Berry, Anne Jobling, Monica Cuskelly

# Outcomes

Slower rate but achieved milestones.

Physiotherapy book for parents of young children and also 'Play Move and Grow' book

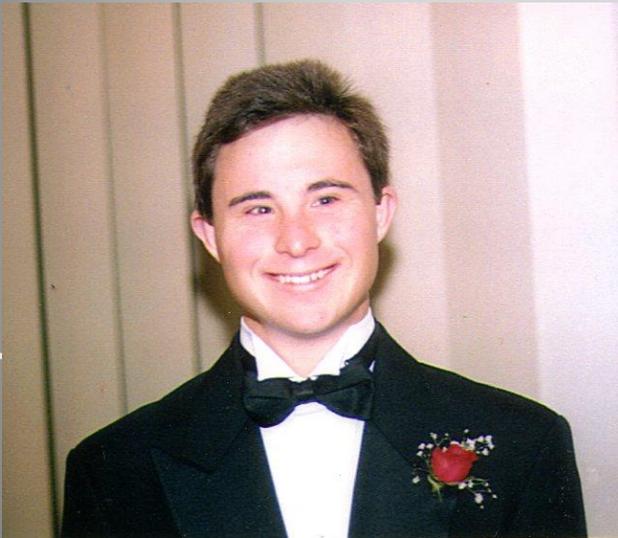
Poor balance and variable gross & fine motor skills.

Limited understanding of how to maintain health and well-being.

# Ongoing focus now

## Well-being and Mental Health Studies

- \* Mental Health Study - Monica Cuskelly, Anne Jobling
- \* Latch-On Resource Unit – Karen Moni, Anne Jobling & Jan Lloyd.



Mathematics (LYLAC) – Rhonda Faragher & Monica Cuskelly



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# Discussion and Conclusion

Dispelling myths – One parent said: ‘.... maybe I gave up too soon, but I listened to what I was told. He had done as much as he was going to do....’ (2017)

All different – variable and variation in development

Need for ongoing opportunities to continue learning.

Influence of literacy learning on employability

Mental health: new challenging aspect of adulthood.