The Stepping Stones Triple P Project

A public health approach to supporting parents and caregivers of children with disabilities

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(with Kylie Gray, Kate Sofronoff)

NHMRC Program Grant
Mental Health of children with ID
Lessons from the Australian Child to Adult Development Study

Funded NH&MRC, NIH, Apex, Rotary

Helping Young People Grow!

Monash University,
Centre for Developmental Psychiatry and Psychology

University of Sydney,
Brain and Mind Research Institute

Centre for Autism Research, Education, and Services (CARES)
ACAD team

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Dr. Kerry Bull
Melissa Kiomall
Caroline Keating et al.

University of Sydney
Professor Stewart Einfeld
Professor Trevor Parmenter
Dr Sue Hartog
Sian Horstead et al.
LONGITUDINAL STUDY

Epidemiological sample (592)

- Down (74)
- Prader-Willi (61)
- Williams (67)
- Fragile X (64)
- Autism (124)

Representative sample of young people (4-18 years) with intellectual disability
Family resources

Parental/family
- stability
- mental health
- skills
- participation

Social support & provision

Life events
school

Temperament

Genetic aetiology

Medical Disorder
(neurological, sensory)
Drugs

Cognitive skills, IQ level

Youth person's adjustment
(impairment, activities, participation)
Developmental Behaviour Checklist (Einfeld & Tonge)
Measure of psychopathology

Mean Behaviour Problem Score

Time 1

Time 4

Epidemiological
Autism
Down
Fragile X
Williams
Prader Willi
One-way analysis of variance revealed significant group differences at p < .05
PARENT MENTAL HEALTH (GHQ)

Mean score

Low TBPS   High TBPS

Significant

Low TBPS

High TBPS

Mean score

Low TBPS

High TBPS

Significant
Change in parental mental health: Epidemiological sample

Mean GHQ score

Time 1  Time 2  Time 3  Time 4
PREDICTORS & CORRELATES OF PSYCHOPATHOLOGY

**Significant**
- Time 1 psychopathology
- Temperament
- Ability to speak
- Social networks
- Family functioning
- Parental mental health

**Not Significant**
- Child’s age
- Child’s sex
- IQ level
- Socioeconomic status
- Intact family
- Stressful life events
Conclusion

- findings support development of early intervention and prevention programmes
  - targeted at young people with high levels of disturbance (e.g., disruptive behaviours, anxiety, autism)

Best Practice

A family-centred approach to service delivery is considered to be a best practice in early intervention services.

Sanders meets Einfeld & Tonge:

Mental Health of Young People with Developmental Disabilities

NHMRC Program

Stepping Stones - Triple P Positive Parenting for parents of children with a disability
To decrease the prevalence of emotional and behavioural problems in children with a disability at a population level
Why families of children with disabilities need parenting support

- Children with disabilities have 3 - 4 times the rates of behavioural and emotional problems (Einfeld & Tonge, 1996)
- Parents and caregivers of children with disabilities experience greater parental stress
- Parental stress is related to the level of behavioural problems their child experiences
- There is a low level of participation in evidence based programs

Stepping Stones - Triple P Positive Parenting for parents of children with a disability
My Say Survey: for Parents and Professionals

Stepping Stones - Triple P Positive Parenting for parents of children with a disability
My Say Survey Results
Victoria and Queensland

Stepping Stones - Triple P Positive Parenting for parents of children with a disability
Preliminary analyses based on N = 1040 parents

- What is your child’s age now?
- What is your child’s type of disability?
- What are your child’s daytime activities?
- How supported do you feel within your family?
- How supported do you feel outside your family?
- Results from parenting measures

Stepping Stones - Triple P Positive Parenting for parents of children with a disability
What is your child’s age now?

<table>
<thead>
<tr>
<th>Child's Age</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 years</td>
<td></td>
</tr>
<tr>
<td>3 years</td>
<td></td>
</tr>
<tr>
<td>4 years</td>
<td></td>
</tr>
<tr>
<td>5 years</td>
<td></td>
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<tr>
<td>6 years</td>
<td></td>
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<tr>
<td>7 years</td>
<td></td>
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<tr>
<td>8 years</td>
<td></td>
</tr>
<tr>
<td>9 years</td>
<td></td>
</tr>
<tr>
<td>10 years</td>
<td></td>
</tr>
</tbody>
</table>

Victoria

Queensland
Demographics
Type of Disability?

- Acquired brain injury
- Asperger's Syndrome
- Autism
- Autism Spectrum Disorder
- PDD-NOS
- Blind/Vision Impairment
- Cerebral Palsy
- Childhood Disintegrative Disorder
- Deaf/Hearing Impairment
- Down Syndrome
- Epilepsy
- Foetal Alcohol Syndrome
- Fragile X Syndrome
- Intellectual disability/Developmental Delay
- Language Delay/Disorder
- Motor Neurone Disease
- Multiple Sclerosis
- Muscular Dystrophy
- Para/quadri (Tetra)/hemiplegia
- Prader Willi Syndrome
- Rett Syndrome
- Spina Bifida
- Tuberous Sclerosis
- Velo Cardio Facial Syndrome
- Williams Syndrome
- Other chromosome disorder
- Other neurological disability
- Other physical disability

Percentage

VIC
QLD

[Bar chart showing the percentage distribution of each disability type for VIC and QLD.]
What are your child’s daytime activities?

- Early Intervention
- 3 Year Old Kinder
- 4 Year Old Kinder
- Child Care Centre
- Playgroup
- Mainstream with aid
- Mainstream without aid
- Special program mainstream
- Special school
- Home schooled
- No formal program
- Other

Percentage

VIC
QLD
How supported do you feel in your parenting role (within the family)?

- Supported very often
- Supported often
- Supported sometimes
- Supported rarely
- Not supported at all

**Percentage**

<table>
<thead>
<tr>
<th>Category</th>
<th>VIC</th>
<th>QLD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supported very often</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supported often</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supported sometimes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supported rarely</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not supported at all</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Legend**

- VIC
- QLD
How supported do you feel in your parenting role (outside the family)?

![Bar chart showing the percentage of support received in VIC and QLD.]

- Supported very often
- Supported often
- Supported sometimes
- Supported rarely
- Not supported at all

VIC
QLD
CAPES  Parent efficacy scale
(Higher scores = greater parent confidence)
CAPES Child sub-scales
(Higher scores = greater difficulties)
Parent and Family Adjustment Scale
(Higher scores = greater difficulties)

Mean Item Score

Parenting Practices
Parental Adjustment
Parental Teamwork
Family Relationships

VIC
QLD

Average Range
Parent and Family Adjustment Scale

Parenting Practices
Parental Adjustment
Parental Teamwork
Family Relationships

Mean Item Score

VIC
QLD

Average Range

Parenting Practices
Parental Adjustment
Parental Teamwork
Family Relationships
### Developmental Behaviour Checklist

<table>
<thead>
<tr>
<th>Category</th>
<th>VIC</th>
<th>QLD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Behaviour Problem Score</td>
<td>78%</td>
<td>82%</td>
</tr>
<tr>
<td>Disruptive/Antisocial Behaviour</td>
<td>78%</td>
<td>78%</td>
</tr>
<tr>
<td>Self Absorbed</td>
<td>76%</td>
<td>80%</td>
</tr>
<tr>
<td>Communication Disturbance</td>
<td>78%</td>
<td>80%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>86%</td>
<td>86%</td>
</tr>
<tr>
<td>Social Relating</td>
<td>74%</td>
<td>76%</td>
</tr>
</tbody>
</table>

**Clinical Cut Off**
- Average Range

**Mean Item Score & Percentile**
- 0 0.2 0.4 0.6 0.8 1 1.2 1.4 1.6 1.8 2
Preliminary analyses based on N = 1530 professionals

- What types of child disability do you currently work with?
- What is your current work role?
- Availability of parenting programs in your community

Stepping Stones - Triple P Positive Parenting for parents of children with a disability
Type of Disability Professionals are Working with.
Professional – Work Role

- Case Management Worker
- Counsellor
- Disability Support Worker
- Early Intervention Specialist
- Family Worker
- General/Medical Practitioner
- Nurse
- Occupational Therapist
- Paediatrician
- Physiotherapist
- Psychiatrist
- Psychologist
- School Guidance Officer
- School Psychologist
- Social Worker
- Speech Pathologist
- Teacher
- Other

Percentage

VIC
QLD
Availability of parenting programs in your community?
The Challenge

Increase the number of parents and caregivers of children with a disability who complete evidence-based parenting programs & professionals to deliver them.

To enhance parenting competence and confidence at a population level.

To reduce the prevalence of child social, emotional and behavioural problems at a population level.
Rationale for Selecting Stepping Stones

- Strong evidence base supporting the success of all levels of the program
- High level of training for health professionals (no profession excluded)
- Dedicated interactive website for professionals offering support, resources & disability specific information
- No ‘one size fits all’ approach & tailored for specific conditions e.g. ASD, PWS, DS, WS.
- Offers increasing levels of support to meet parents’ different needs

MONASH University
What is the Stepping Stones Triple P Program?