CHW School-Link:

Jodie Caruana, School-Link Coordinator
jodie.caruana@health.nsw.gov.au
www.schoollink.edu.au

Department of Psychological Medicine
Children's Hospital at Westmead (CHW)
Sydney Children's Hospital Network

Acknowledgements & Resources:

- Dr David Dossetor, Director Mental Health, CHW
- Dr Phil Ray, Senior Psychologist, CHW
- Hebah Saleh, School-Link, CHW
- Dr Stewart Einfeld, Faculty of Health Sciences, Brain and Mind Research Institute
- Dossetor D, Donna White, Leslie Whatson (Eds).

"Mental health for children and adolescents with intellectual disability: a framework for professional practice." IP Communications: Melbourne. 2011.

Abbreviations

- *ADHC:* Ageing, Disability and Home Care
- *CAMHS:* Child and Adolescent Mental Health Service
- *CB:* Challenging Behaviour
- *C&A:* Children and Adolescents
- *DEC:* New South Wales Department of Education and Communities
- *DGO:* District Guidance Officers from DEC
- *DD:* Developmental Disability
- *ID:* Intellectual Disability
- *IDD:* Intellectual and Developmental Disabilities
- *MH+ID:* Mental Health and Intellectual Disability
- *PD:* Psychiatric Disorder
- *PPEI:* Prevention, Promotion and Early Intervention
- *SSP:* School for Specific Purposes

Outline

- School-Link
- Prevention, Promotion & Early Intervention
- Stepping Stones Triple P
- Resources

OVERVIEW OF SCHOOL-LINK

Background to School-Link

- NSW School-Link Program began in 1999.
- 2009 CHW granted funding to focus on children and adolescents with an intellectual disability.

CHW School-Link for ID/DD

Background to School-Link

CHW School-Link focuses on three main areas for children and young people with an intellectual/developmental disability:

•Mental Health Prevention, Promotion and Early Intervention Programs

•Mental Health Training and Education and Awareness Raising

•Assisting in identifying Mental Health Pathways to Care

ID support classes in schools

- 107 SSPs in NSW
- 60 Government SSPs catering for ID

School Type	*IM*	*IO/IS*	*IS*	*MC*	*Total*
support classes in special schools	-	428	27	62	**517**
support classes in regular schools	351	449	10	383	**1193**
distance education support unit classes	3	8	-	-	**11**
Total	**354**	**885**	**37**	**445**	**1721**

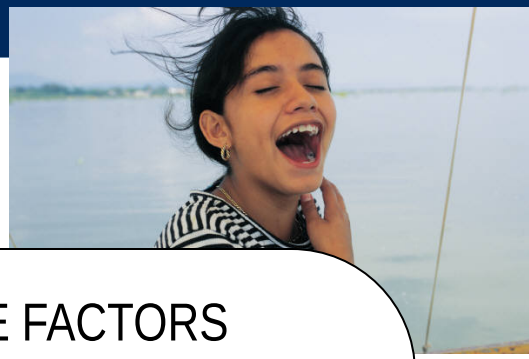
Adapted from DEC, 2013

Key
IM Mild ID
IO Moderate ID
IS Severe ID
MC Multi-categorical (moderate/high support needs)

Table 1: Distribution of ID support classes in NSW Government Schools by School Type and level of Intellectual Disability 2013

MENTAL HEALTH PREVENTION PROMOTION & EARLY INTERVENTION

Risk Factors and Protective Factors potentially influencing the development of mental health problems and mental disorders in individuals (particularly children)



Individual Factors

RISK FACTORS
- prenatal brain damage
- prematurity
- birth injury/ complications / low weight
- physical/ intellectual disability
- poor health in infancy
- insecure attachment in infant/child
- low intelligence
- difficult temperament
- chronic illness
- poor social skills
- low self –esteem
- alienation
- impulsivity

PROTECTIVE FACTORS
- easy temperament
- adequate nutrition
- attachment to family
- above average intelligence
- problem-solving skills
- social competence/ skills
- good coping style
- optimism
- moral beliefs
- values

Family/ Social Factors

RISK FACTORS

- having a teenage mother or single parent
- absence of father in childhood
- large family size
- antisocial role models
- family violence/disharmony, marital discord
- poor supervision & monitoring of child
- low parental involvement
- neglect in childhood
- long term parental unemployment
- criminality in parent
- parental subs misuse and/or mental disorder
- harsh or inconsistent discipline style
- social isolation
- experiencing rejection
- lack of warmth and affection

PROTECTIVE FACTORS

- supportive caring parents
- family harmony
- secure and stable family
- small family size
- more than two years between siblings
- responsibility within the family
- supportive relationship with other adult
- strong family norms and morality

School Context

RISK FACTORS
- bullying
- peer rejection
- poor attachment to school
- inadequate behaviour management
- deviant peer group
- school failure

PROTECTIVE FACTORS
- sense of belonging
- positive school climate
- pro social peer group
- required responsibility and helpfulness
- opportunities for some success and recognition of achievement
- school norms against violence

(Commonwealth Department of Health and Aged Care 2000)

Life Events & Situations

RISK FACTORS

- abuse
- school transitions
- divorce/family breakup
- death of family member
- physical illness/ impairment
- unemployment/ homelessness
- incarceration
- poverty / economic insecurity
- job insecurity
- unsatisfactory work relationships
- workplace accident/injury
- living in nursing home/ hostel
- caring for someone with a disability
- war or natural disasters

PROTECTIVE FACTORS

- involvement with significant other person (partner/mentor)
- availability of opportunities at critical turning points or major life transitions
- economic security
- good physical health

(Commonwealth Department of Health and Aged Care 2000)

Community & Cultural Factors

RISK FACTORS
- socioeconomic disadvantage
- social or cultural discrimination
- isolation
- neighbourhood violence and crime
- population density and housing conditions
- lack of support services including- transportation, shopping, recreational facilities

PROTECTIVE FACTORS
- sense of connectedness
- attachment to and networks within the community
- participation in community group
- strong cultural identity and ethnic pride
- access to support services
- community/ cultural norms against violence

(Commonwealth Department of Health and Aged Care 2000)

Mental Ill Health Prevention

- Prevention interventions work by focussing on reducing risk factors and enhancing protective factors associated with mental ill-health.

Hunter Institute for Mental Health (2011)

Mental Health PPEI Programs

- Lack of empirical studies on PPEI programs with ID.
- **Mental Health Promotion** programs report applicability to 'special needs' but not specified for ID let alone mild, mod or severe disability level.
- **Early intervention/treatment approaches** only when problems are recognised but problems in identifying problems.
- Only a small amount occurring in SSPs
- No programs targeting adolescents with ID/DD.

Program	Age	Aim	Target	Children	Authors
Stepping Stones Triple P	3-12	Positive parenting	parents	disabilities &disruptive behaviour	Roberts et al 2006
Signposts	3-16		parents	Develop. delay or an intellectual disability	Parenting Research Centre (PRC) & RMIT 2008
Stop Think Do	4-15	Problem solving	Children parents	anxiety, ADHD, Aspergers	Petersen 2002
The Alert Program	8-12	Arousal regulation	children	sensory processing &/or learning impairment	Williams & Shellenberger, 1996
Social Decision Making	6-13	Emotions and problem solving	children	Learning disabilities	Elias & Bruene Butler, 2005
The Paths Curriculum	4-9		Children	Learning disabilities	Greenberg & Kusche 1998
Emotion Based Social Skills Training	8-14		Parents Teachers children	With ASD and mild ID	Ratcliffe, Grahame, & Wong, 2010
Secret Agent Society	8-12			HFASD	Beaumont & Sofronoff (2008)

Prevention Framework in Schools

1. A positive school community
- Sense of belonging and inclusion by a welcoming and friendly environment.
- Collaborative sense of involvement of students ,staff, parents, community.
- Examples, PBL or PBIS

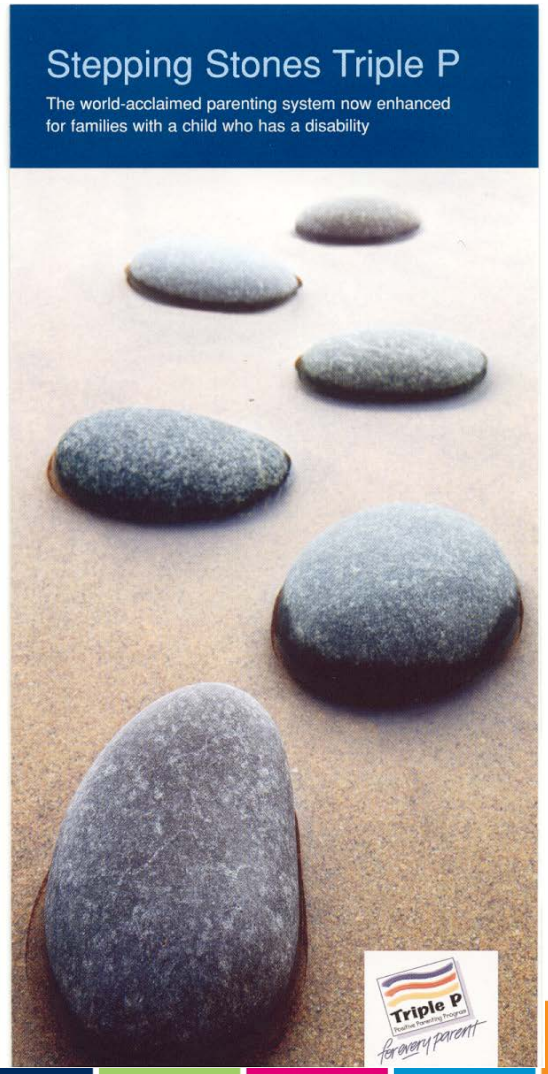
2. Social & emotional learning for students/ Student Resilience
- Emotion Based Social Skills Training
- Stop Think Do
- The Paths Curriculum
- Social Decision Making
- The Alert Program
- The Secret Agent Society

3. Parenting support & education
- Specialised training programs
  - Stepping Stones Triple P
  - Emotion Based Social Skills Training
- Other sessions that collaborate with disability or health services on communication or behaviour

4. Early intervention for students experiencing mental health difficulties
- Behavioural approaches
- Augmented and Alternative Communication
- Cool Kids Child Anxiety Program ASD Adaption

STEPPING STONES TRIPLE P PARENTING PROGRAM

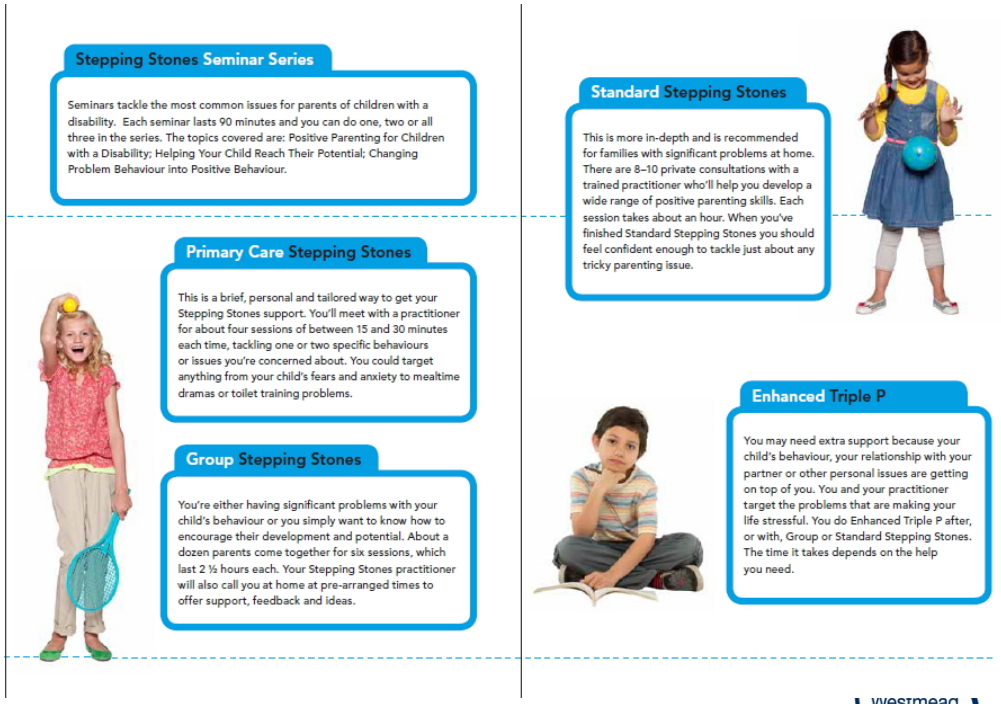
Stepping Stones Triple P



- Adapted from Triple P system (Sanders, 2012; Prinz et al, 2009)
- A multi-level parenting and family support strategy for families of children with disabilities (Mazzucchelli & Sanders, 2011*)

How is SSTP delivered?

- Media campaigns
- Website
- Seminars
- Group Programs
- One-on-one



Need for Parental 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

Hypothesis

Implementation of GSSTP in schools will:

- Improve the behaviour of children at home and school.
- Have a positive impact on mental health, behaviour management skills and confidence of parents.

Design

- Group delivery within a school environment, by co-facilitators (School + ADHC)
- Pre, Post and 3 Month Follow Up testing by parents and class teachers.
- No control group (unfortunately).
- Our sample was not randomised, an opportunity sample.

Participants

- For Phase 2: Parents or caregivers of a child attending a special education school that caters for intellectual disability.

- For Phase 3: Parents or caregivers of a child attending a special education school, regular public school, private school, catholic school and/or unit that caters for autism.

- Recruitment of parents by the school.

Measures

1. Family Background- Family Background Questionnaire (Adapted from Zubrick *et al*, 1995).
2. Child Adjustment- Developmental Behaviour Checklist – Parent and Teacher Versions (Einfeld and Tonge, 2002).
3. Parenting Style- Parenting Scale (Arnold *et al*, 1993).
4. Parenting Confidence- Parenting Tasks Checklist (Sanders and Woolley, 2005).
5. Parental Adjustment- Depression, Anxiety and Stress Scale (Lovibond and Lovibond, 1995)

Phase 2 & Phase 3

Phase 2 (2012) focussed on children with ID

- 56 sets of parents of children with ID.
- 37 of the those children also had a dual diagnosis ASD
- Groups were in 10 special education schools and 1 regular school with support class.

Phase 3 (2013) focussed on children with ASD

- 95 Sets of Parents with children with ASD
- Groups were in 12 Schools with various settings e.g. SSP's, Private Schools, Units etc.


RESULTS

Phase 2: 2012 ID

Developmental Behaviour Checklist - Parent

- Disruptive/Antisocial: 18% decrease*
- Self Absorbed: 6% decrease
- Communication Disturbance: 1% decrease
- Anxiety: 10% decrease
- Social Relating: 11% decrease
- Total: 10% decrease*

All scores stayed above Clinical cutoff

*=<.05 **=<0.01 (significance levels)

Phase 2: 2012 ID

Developmental Behaviour Checklist - Teacher

- Disruptive/Antisocial: 29% decrease**#
- Self Absorbed: 26% decrease**#
- Communication Disturbance: 16% decrease*
- Anxiety: 24% decrease**
- Social Relating: 32% decrease**#
- Total: 25% decrease**#

*=<.05 **=<0.01 (significance levels)
= Change to below Clinical cutoff

Phase 3: 2013 ASD

Developmental Behaviour Checklist – Parent

- Disruptive/Antisocial: 23% decrease**
- Self Absorbed: 20% decrease**
- Communication Disturbance: 13% decrease**
- Anxiety: 15% decrease**
- Social Relating: 16% decrease**#
- Total: 15% decrease**

All scores except # stayed above Clinical cutoff
3 Month Follow Up: All maintained or dropped further.
E.g. Total DBC Score 82% -> 66% -> 60% (cutoff 58%)

= Change to below Clinical cutoff
**=<0.01 (significance levels)

Phase 3: 2013 ASD

Developmental Behaviour Checklist – Teacher

- Disruptive/Antisocial: 9% decrease
- Self Absorbed: 7% decrease
- Communication Disturbance: 3% decrease
- Anxiety: 16% decrease
- Social Relating: 6% decrease
- Total: 8% decrease

- All scores below Clinical cutoff

*=<.05 **=<0.01 (significance levels)

Phase 3: 2013

DBC Average Totals

	Parent Total 2012 ID	Teacher Total 2012 ID	Parent Total 2013 ASD	Teacher Total 2013 ASD
Pre	63.91	51.46	63.98	37.39
Post	58.11	40.38	51.43	34.32
3 Month Follow Up			47.48	33.82

Phase 2 & 3
2012 vs 2013

Parenting Scale

	2012 ID	2013 ASD
Laxness	19% Decrease**	16% Decrease**
Overreactivity	18% Decrease**	14% Decrease**
Verbosity	22% Decrease**	13% Decrease**

**=<0.01 (significance levels)

Phase 2 & 3
2012 vs 2013

Parenting Tasks Checklist

	2012 ID	2013 ASD
Setting Efficacy	10% Increase**	13% Increase**
Behaviour	16% Increase**	20% Increase**

**=<0.01 (significance levels)

Phase 2 & 3
2012 vs 2013

DASS-21

	2012	2013
Depression	55% Decrease** (Mild -> Normal)	57% Decrease** (Extremely Severe -> Moderate)
Anxiety	52% Decrease** (Normal -> Normal)	50% Decrease** (Severe -> Mild)
Stress	43% Decrease** (Normal -> Normal)	60% Decrease** (Severe -> Mild)

Program halves presentation regardless of intensity

**=<0.01 (significance levels)

GSTTP Conclusions

- School-based delivery of GSSTP is an effective early intervention for children with ID and ASD.
- Parent stress, anxiety, depression levels decreased whilst confidence in parenting increased.
- Benefits continue after the program is complete.
- Collaboration beneficial.
- Additional by products of the groups included increased peer support and improved parent/school relations.

Parents and staff from Beverley Park School.

The Stepping Stones Triple P Project

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

Professor Stewart Einfeld

THE UNIVERSITY OF SYDNEY

THE UNIVERSITY OF QUEENSLAND AUSTRALIA

MONASH University

Triple P Positive Parenting Program

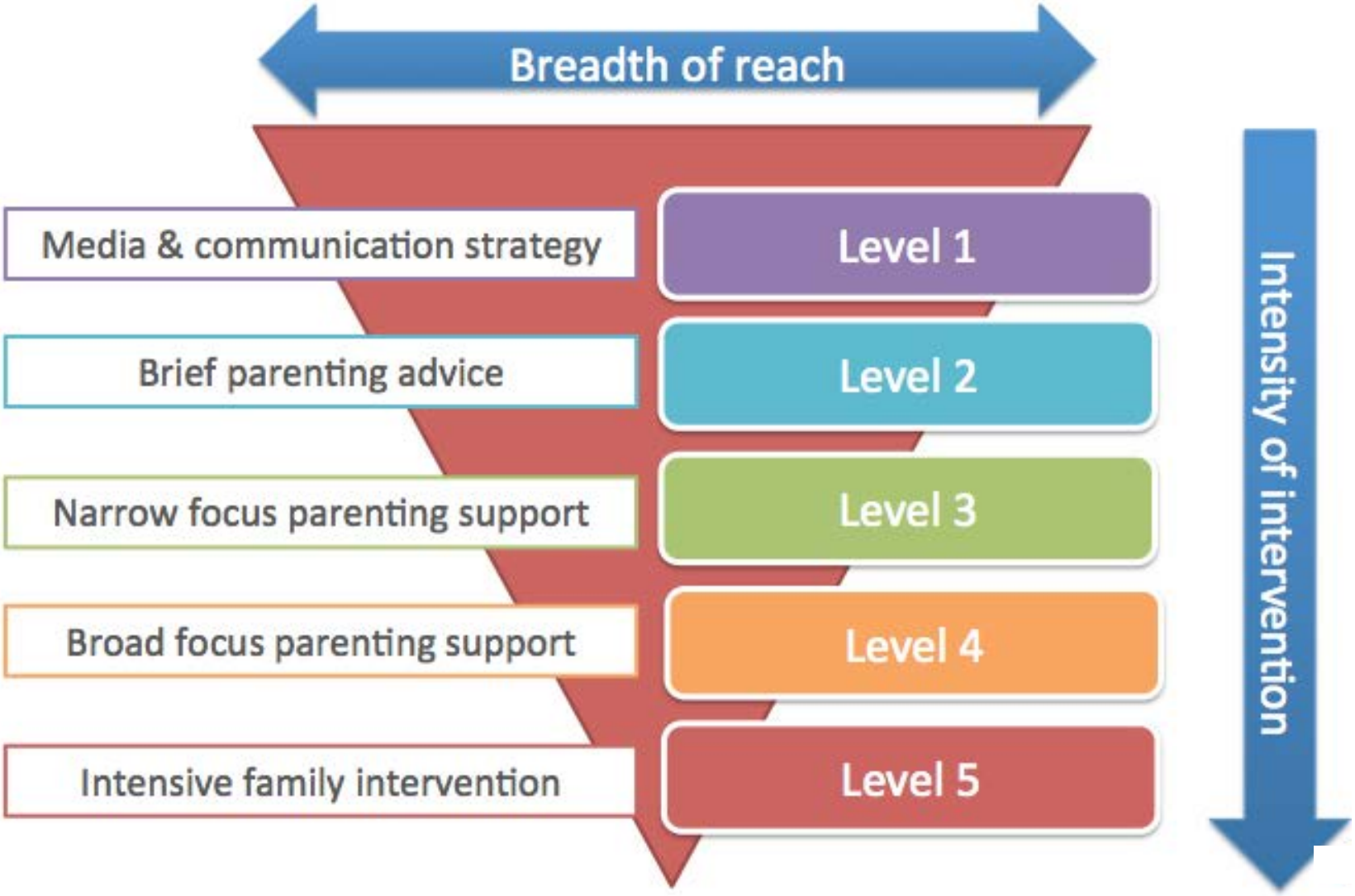
THE CHALLENGE

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

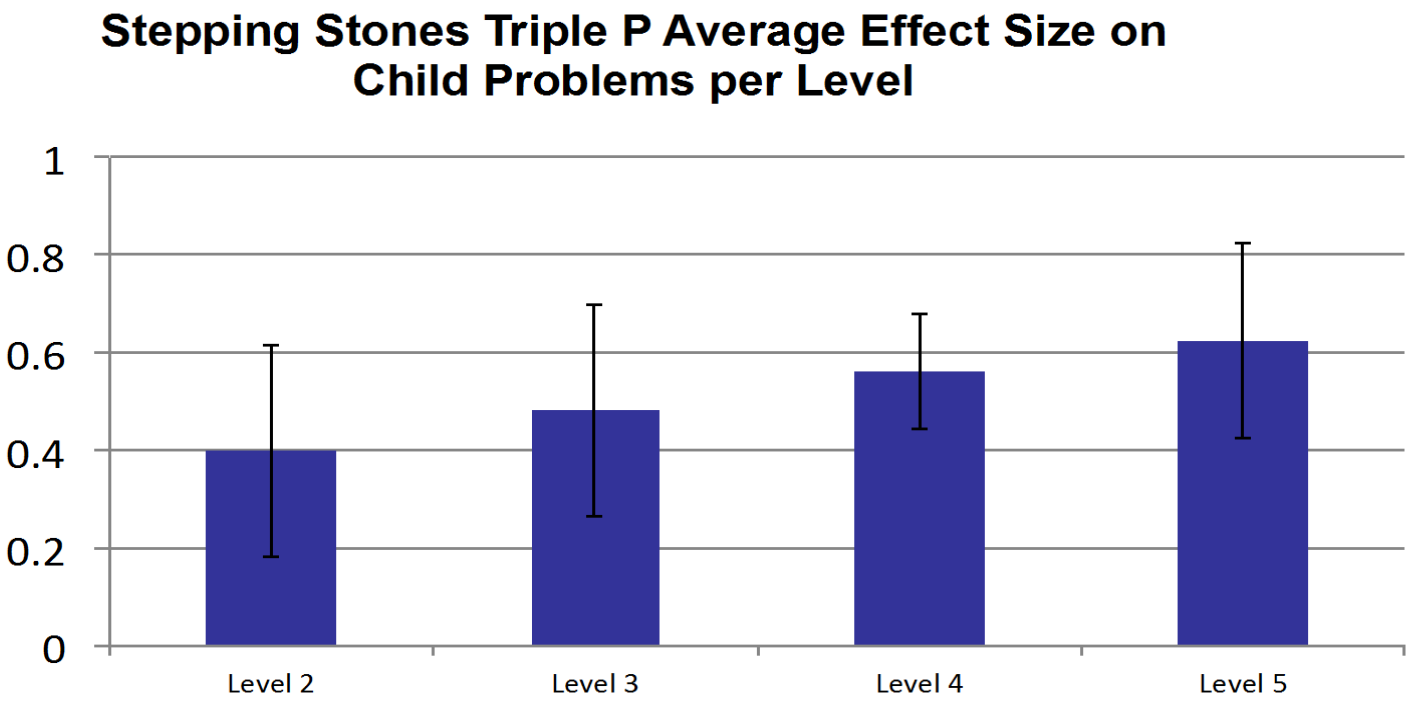
To enhance parenting competence and confidence at a population level

To reduce the prevalence of child social, emotional and behavioural problems at a population level

The Stepping Stones Triple P system of intervention



META-ANALYSIS: STEPPING STONES TRIPLE P



Tellegen, C.L. & Sanders, M.R. (2013). Stepping Stones Triple P: A systematic review and meta-analysis. *Research in Developmental Disabilities, 34,* 1556-1571.

So it has efficacy, but is it effective?

The Triple P Stepping Stones (SSTP) Project

- National Health & Medical Research Council (NHMRC) funded Program Grant
- Aims:
  - To decrease the prevalence of emotional and behavioural problems in children with a disability in the community
  - Determine the public health benefit & cost-effectiveness of the SSTP program at a population level
- Delivered as a community wide strategy across three states: Queensland, Victoria, and New South Wales

PROJECT DESIGN

Stage 1

- "My Say" population level survey of parents, caregivers and professionals

Stage 2

- NSW roll-out of Stepping Stones Triple P parenting program

Stage 3

- Population level survey of parents and caregivers, and professionals to assess changes in levels of emotional and behavioural problems

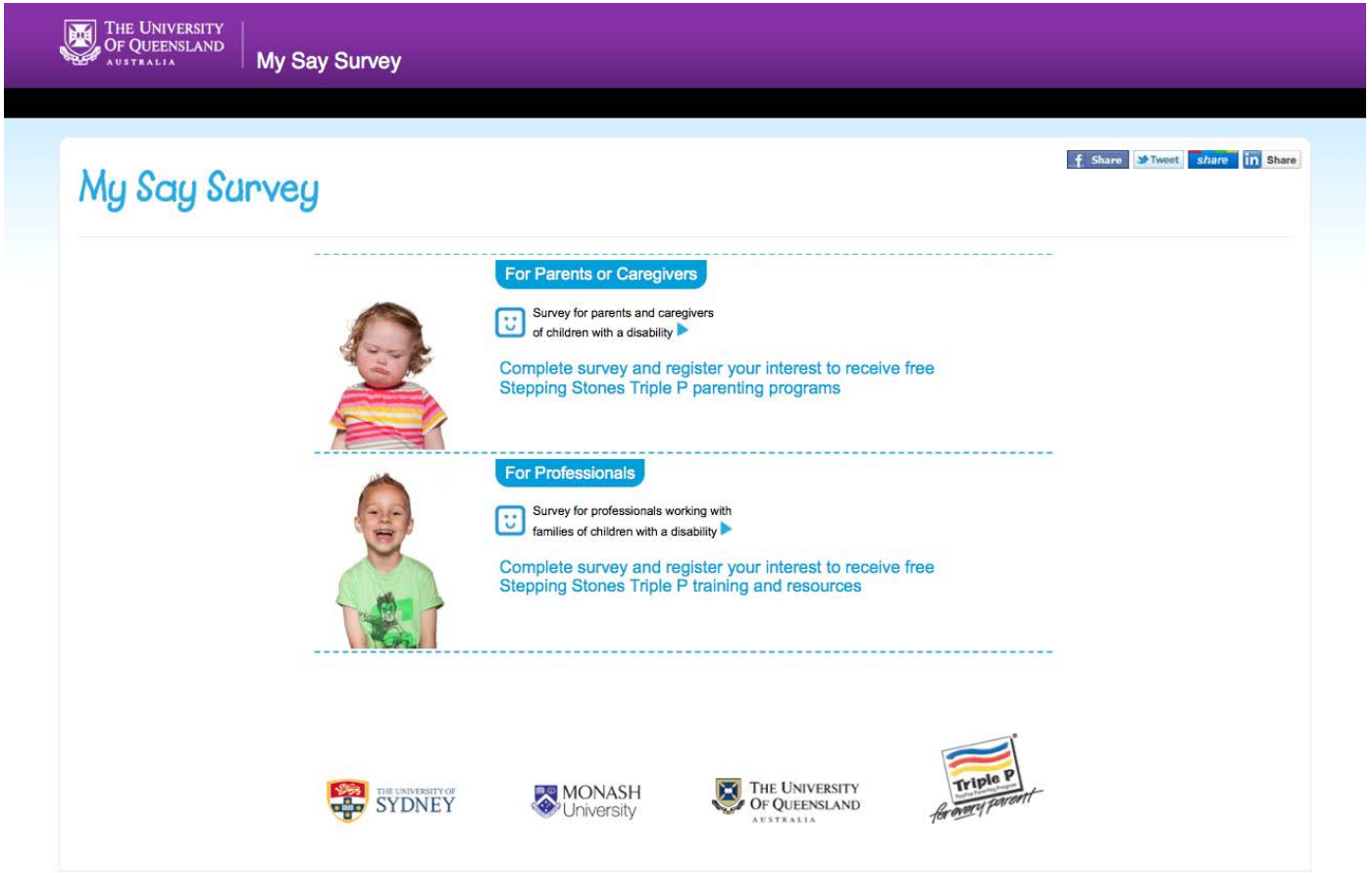
STAGE 1: MY SAY SURVEY

- Parents and caregivers of children with a disability aged 2-10 years

- Professionals who work with children with disabilities and their families (e.g., teachers, psychologists, occupational therapists, speech therapists, disability support workers, case management workers).

MY SAY WEBSITE

www.mysay.org.au



STAGE 2: TRAINING OF PROFESSIONALS

- Free Stepping Stones training will be offered to professionals who work with children with a developmental disability.
- Professionals can indicate their interest in receiving Stepping Stones training when they complete the “My Say” survey.
- Professionals will be chosen based on their capacity to deliver the program to families.

STAGE 2: SUPPORT FOR FAMILIES

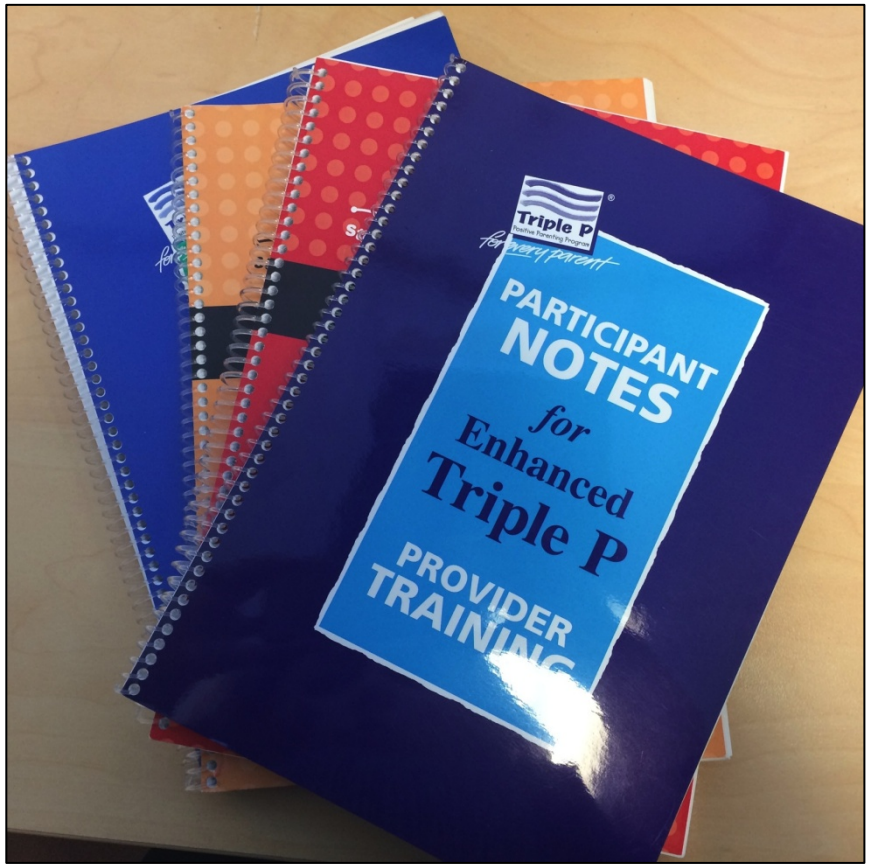
- NSW roll-out of the Stepping Stones program free of charge to all eligible parents and caregivers of children with disabilities aged 2-12 years.
- This includes a sub-set of parents and caregivers of children aged 2-10 years with an intellectual disability or developmental delay. These parents and children will be followed up more intensely.

The SSTP strategies

PROMOTING A POSITIVE RELATIONSHIP • Spending quality time with your child • Communicating with children • Showing affection	ENCOURAGING DESIRABLE BEHAVIOUR • Descriptive praise • Positive attention • Providing other rewards • Engaging activities • Setting up activity schedules
TEACHING NEW SKILLS AND BEHAVIOURS • Setting a good example • Using physical guidance • Incidental teaching • Ask-Say-Do • Teaching backwards • Behaviour charts	MANAGING MISBEHAVIOURS • Using diversion to another activity • Ground rules • Directed discussion • Planned ignoring • Clear, calm instructions • Teaching children to communicate • Logical consequences • Blocking • Brief Interruptions • Using quite time • Using time-out for serious misbehaviour

SSTP resources

Workbooks



Primary care booklets

Behavioural phenotypes and syndrome specific modules

As part of the project we will create resources for 7 disability syndromes groups and their specific behaviour phenotypes:

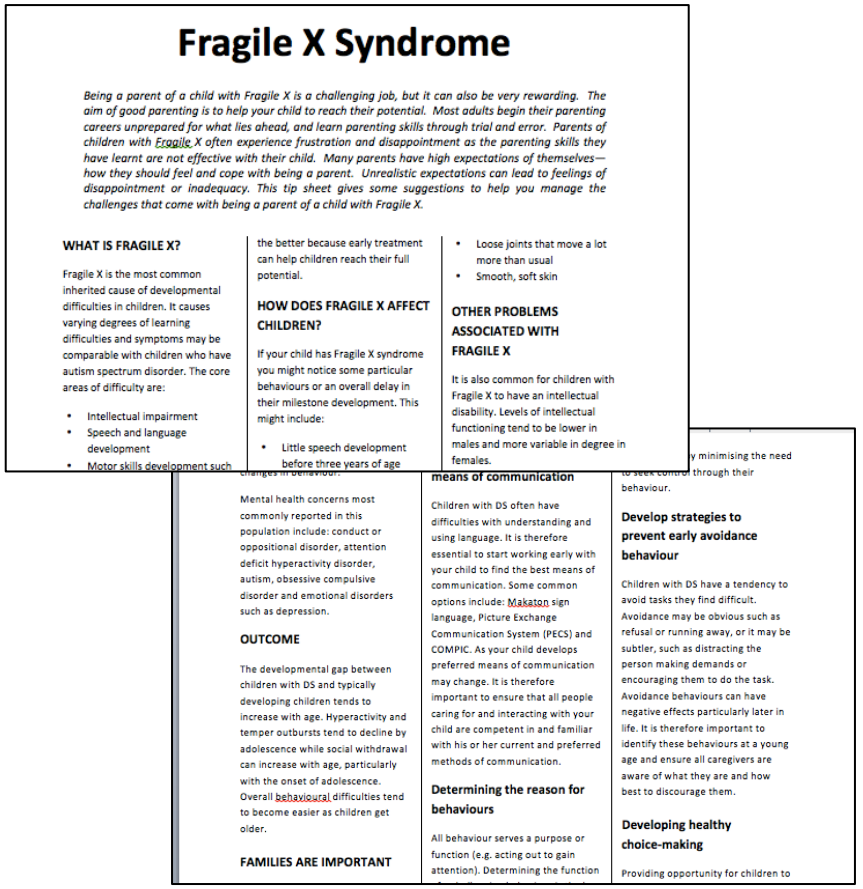
- Autism Spectrum Disorder
- Down Syndrome
- Fragile X
- Fetal Alcohol Spectrum Disorders
- Williams Syndrome
- Prader Willi Syndrome
- Velo-Cardio-Facial Syndrome/ 22q Deletion Syndrome

SSTP tip sheets for parents

The modules include three resource sheets for each syndrome

› Parent tip sheets about:

- The nature of the syndrome
- Behavioural phenotype
- Behaviour management strategies specific to their child's syndrome



Fragile X Syndrome

Being a parent of a child with Fragile X is a challenging job, but it can also be very rewarding. The aim of good parenting is to help your child to reach their potential. Most adults begin their parenting careers unprepared for what lies ahead, and learn parenting skills through trial and error. Parents of children with Fragile X often experience frustration and disappointment as the parenting skills they have learnt are not effective with their child. Many parents have high expectations of themselves—how they should feel and cope with being a parent. Unrealistic expectations can lead to feelings of disappointment or inadequacy. This tip sheet gives some suggestions to help you manage the challenges that come with being a parent of a child with Fragile X.

WHAT IS FRAGILE X?

Fragile X is the most common inherited cause of developmental difficulties in children. It causes varying degrees of learning difficulties and symptoms may be comparable with children who have autism spectrum disorder. The core areas of difficulty are:

- Intellectual impairment
- Speech and language development
- Motor skills development such

the better because early treatment can help children reach their full potential.

HOW DOES FRAGILE X AFFECT CHILDREN?

If your child has Fragile X syndrome you might notice some particular behaviours or an overall delay in their milestone development. This might include:

- Little speech development before three years of age

- Loose joints that move a lot more than usual
- Smooth, soft skin

OTHER PROBLEMS ASSOCIATED WITH FRAGILE X

It is also common for children with Fragile X to have an intellectual disability. Levels of intellectual functioning tend to be lower in males and more variable in degree in females.

Mental health concerns most commonly reported in this population include: conduct or oppositional disorder, attention deficit hyperactivity disorder, autism, obsessive compulsive disorder and emotional disorders such as depression.

OUTCOME

The developmental gap between children with DS and typically developing children tends to increase with age. Hyperactivity and temper outbursts tend to decline by adolescence while social withdrawal can increase with age, particularly with the onset of adolescence. Overall behavioural difficulties tend to become easier as children get older.

FAMILIES ARE IMPORTANT

means of communication

Children with DS often have difficulties with understanding and using language. It is therefore essential to start working early with your child to find the best means of communication. Some common options include: Makaton sign language, Picture Exchange Communication System (PECS) and COMPIC. As your child develops preferred means of communication may change. It is therefore important to ensure that all people caring for and interacting with your child are competent in and familiar with his or her current and preferred methods of communication.

Determining the reason for behaviours

All behaviour serves a purpose or function (e.g. acting out to gain attention). Determining the function

y minimising the need to seek control through their behaviour.

Develop strategies to prevent early avoidance behaviour

Children with DS have a tendency to avoid tasks they find difficult. Avoidance may be obvious such as refusal or running away, or it may be subtler, such as distracting the person making demands or encouraging them to do the task. Avoidance behaviours can have negative effects particularly later in life. It is therefore important to identify these behaviours at a young age and ensure all caregivers are aware of what they are and how best to discourage them.

Developing healthy choice-making

Providing opportunity for children to

SSTP Tip sheets for practitioners

› Practitioner tip sheets provide information about:

- Behavioural and cognitive characteristics of the syndrome
- Key points to remember when working with families with a child with the syndrome
- Key links to further information

SSTP syndrome specific strategies

An example of a strategy for children with Prader Willi syndrome

Setting up activity schedules	★	Activity schedules may reduce outbursts, anxiety and repetitive questioning in children with PWS. A visual activity schedule can be used to help children understand what is happening throughout the day including what and when they will be eating. Schedules are also great for helping children prepare for changes in routines and when transitioning between activities.

An example of a strategy for children with Fetal Alcohol Spectrum Disorder

Using behaviour charts	★	Using a behaviour chart with a visual reminder of the reward can be used to teach children with FASD the consequences of appropriate behaviour

EXPECTED BENEFITS

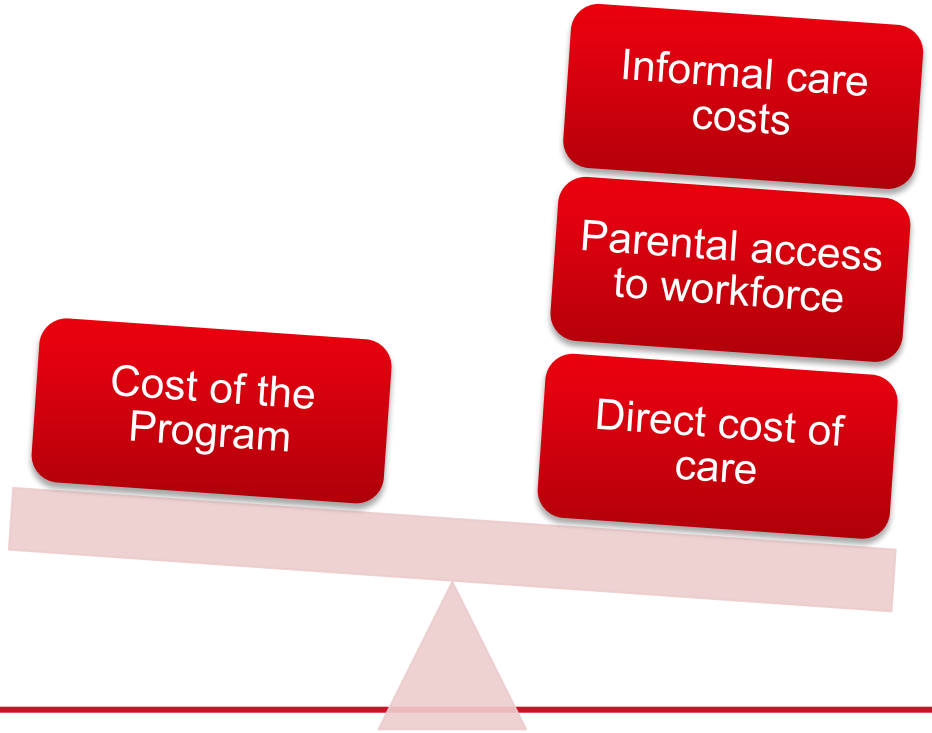
- Increase our understanding of the experiences of families of a child with a disability.
- Provide professionals with access to evidence-based parenting interventions and to increase professional skills in delivering such interventions.
- Improved parenting confidence, refined parenting skills, decreased family stress and a reduction in the children's challenging behaviours).
- Increase population level awareness of the mental health concerns that can affect young people with developmental disabilities.
- Focus on the sustainability of evidence-based parenting programs.

Is it cost-effective? Stepping Stones Triple P: Economic evaluation of a public health intervention

Is the cost of implementing SSTP outweighed by a reduction in cost of care of the child?

Cost of the program

Cost of a child with ID/DD



FURTHER INFORMATION

Email: fhs.steppingstones@sydney.edu.au

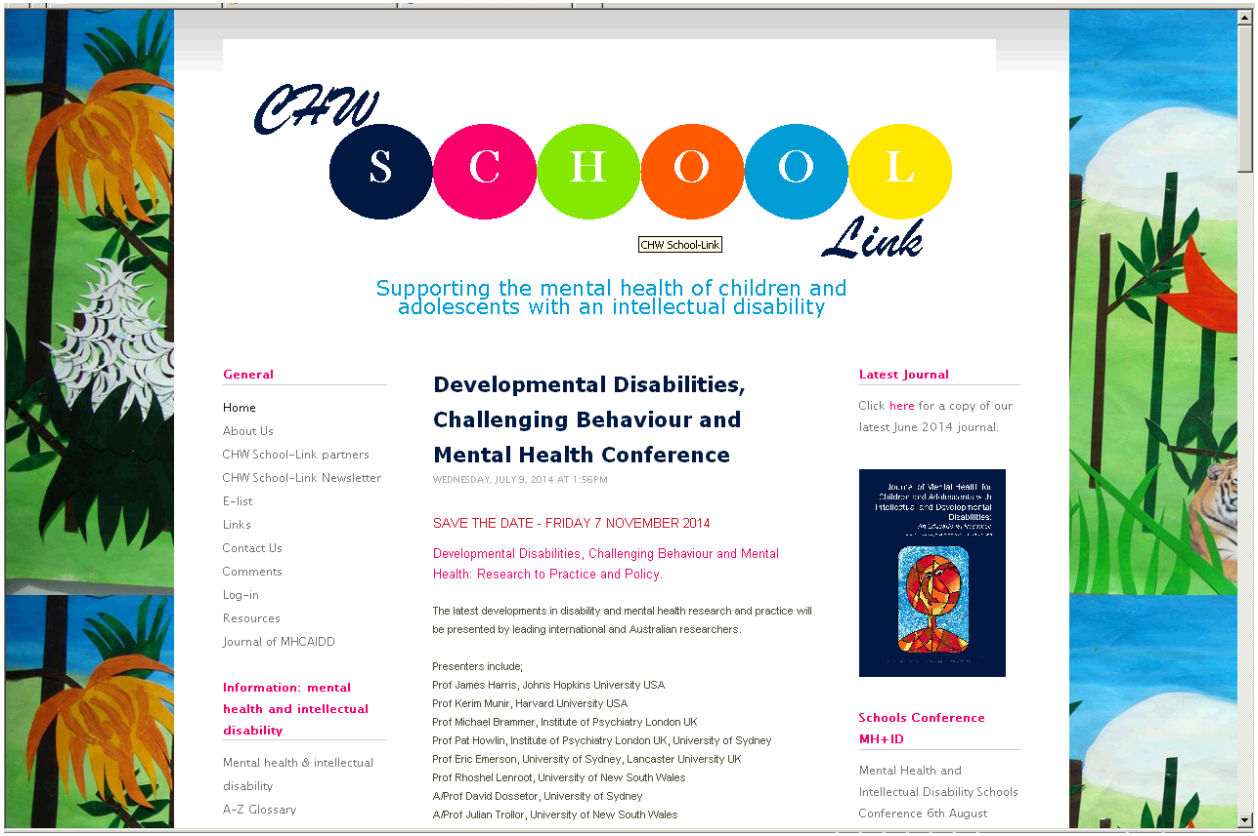
Phone: (02) 9114 4060

www.mysay.org.au

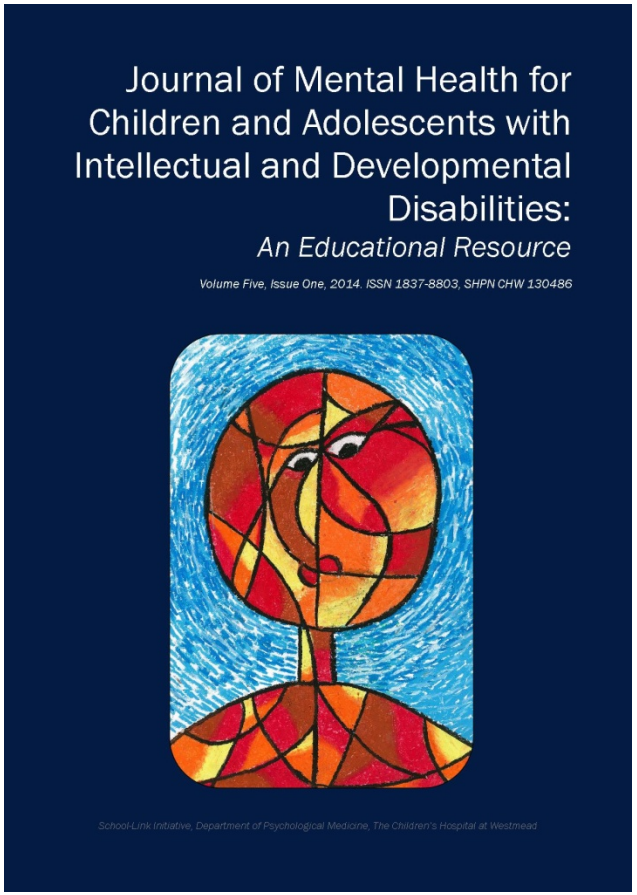
https://www.facebook.com/SteppingStonesTriplePProject

SCHOOL-LINK RESOURCES

www.schoollink.chw.edu.au



Journal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School-Link Initiative, Department of Psychological Medicine, The Children's Hospital at Westmead

General

Home
About Us
CHW School-Link partners
CHW School-Link Newsletter
E-list
Links
Contact Us
Comments
Emotion-based Social Skills Training Feb 2011
Log-in
Resources
Autism and friends at the movies
Journal of MHCAIDD

Information: mental health and intellectual disability

Mental health & intellectual disability
MH problems & disorders
A-Z Glossary
New release book about

The Medicine Cabinet

Clonidine (1.2M)
This article by Judith Longworth in the CHW School-Link Newsletter Volume 4 issue 3/4 explains clonidine.

Fluoxetine (187K)
This article by Judith Longworth in the CHW School-Link Newsletter Volume 2 issue 2 explains the use of fluoxetine.

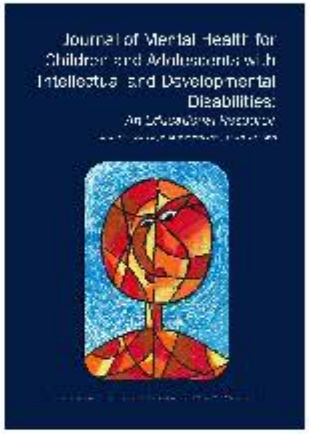
Mood Stabilisers Part 1 (266K)
This article by Judith Longworth in the CHW School-Link Newsletter Volume 3 issue 3/4 explains mood stabilisers used with children and adolescents with an intellectual disability. In part 1 medications discussed include lithium and carbamazepine.

Mood Stabilisers Part 2 (233K)
This article by Judith Longworth in the CHW School-Link Newsletter Volume 4 issue 1 explains mood stabilisers used with children and adolescents with an intellectual disability. In part 2 medications discussed include lamotrigine, topiramate, levetiracetam, gaba pentin and other anticonvulsants.

Obesity and Medications (271K)
This article by Judith Longworth in the CHW School-Link Newsletter Volume 3 issue 1 explains how medications can cause weight gain.Medications

Latest Journal

Click here for a copy of our latest June 2014 journal.



Schools Conference MH+ID

Mental Health and Intellectual Disability Schools Conference 6th August 2014 Revesby Workers Club

E-List

Sign up to our e-list to receive our quarterly journal and from time to time relevant emails about professional development opportunities.

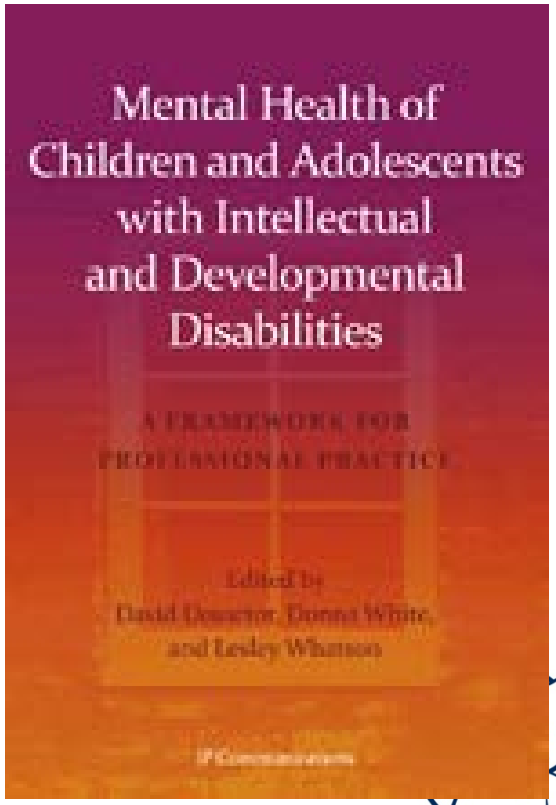
www.schoollink.chw.edu.au

Book

Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities:

A Framework for Professional Practice.

http://www.ipcommunications.com.au .



City 2 Surf 2015

Running as superheros to raise money for kids with Autism at Children's Hospital at Westmead .

Your school is invited to join us in 2015!

Like & share our Facebook page: www.facebook.com/AutismWestmead

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