

#### AUSTRALIA

# Using telehealth technologies to engage and support parents of children with disabilities:

# An evaluation of a novel telehealth parenting programme

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#### **Abstract**

In the absence of effective and appropriate supports, the many unique challenges faced by families of children with disability are likely to be exacerbated. Telehealth technologies offer a promising service-delivery model for disseminating parenting interventions in an accessible, timely and convenient manner with research indicating comparable outcomes between telehealth-based and conventional face-to-face programmes. Regardless of these encouraging findings, few empirically-validated parenting programmes are available in a telehealth delivery modality, with even fewer interventions specifically targeting, and/or including, adaptations to meet the specific needs of parents and caregivers of children with a disability.

The primary aim of the current study is to develop and investigate the efficacy of a telehealth-based parenting intervention for parents of children with a disability. The acceptability of and parent satisfaction with the developed intervention will also be examined as a secondary outcome of the research. Chapter 1 of this dissertation provides a brief overview of the pertinent issues impacting upon the research field and provides a rationale for the current research.

Chapter 2 is a systematic review of the literature in relation to online/telehealth parenting interventions for parents of children with an intellectual or developmental disability. The systematic review was undertaken between October 2013 and April 2014. Eight articles met inclusion criteria; reporting on five trials (three RCTs and two pre-post). All five studies used standardised parent-reported measures of child behaviour. The review provides preliminary evidence as to the efficacy of telehealth-based delivery of programmes in this population, however the small number of studies available and the restricted areas of disability investigated (TBI and FASD), indicates that this is currently a very limited field of research.

Chapter 3 details a qualitative inquiry as to the telehealth-related consumer preferences of parents and carers of children (aged 0-17 years) with mixed disabilities. The survey investigated parents' access to and use of the internet, degree of comfort with a range of online and telehealth-based technologies, the acceptability of online parenting training to this population and preferences in relation to potential delivery modalities and supports. Results were used to inform the development of a telehealth-based parenting intervention for this population.

Chapter 4 provides the protocol of a randomised controlled trial (RCT) of a novel telehealth-based parenting programme for parents and carers of children (aged 2-12 years) with a disability. The theoretical basis, study hypotheses, methods and planned analyses for this protocol are described.

Chapter 5 is a manuscript accepted for publication with *Research in Developmental Disorders*, and reports on the results of the RCT conducted. Ninety-eight parents were randomly assigned to either the telehealth intervention (Triple P Online-Disability) or a control condition (care as usual over 8 weeks). At post-intervention parents receiving the Triple P Online-Disability (TPOL-D) intervention demonstrated significant improvements in parenting self-efficacy and parenting styles when compared with the treatment-as-usual (TAU) control group, but not on child behavioural or emotional problems. At 3-month follow up intervention gains were either maintained and/or enhanced. A significant decrease in parent-reported child behavioural and emotional problems was also detected at this time.

Chapter 6 briefly examines the acceptability of and parent satisfaction with TPOL-D. Using data from 46 completing intervention parents, research questions addressed: (1) intervention adherence; (2) overall satisfaction with TPOL-D; (3) therapist identification and alliance; (4) perceived helpfulness of the individual components of TPOL-D; (5) 'useability' of online modules; and (6) future consumer preference and advocacy issues. Given that no in-person contact occurs at any time in TPOL-D (including the delivery of remote access and technological support), questions of therapist identification and alliance (if any) were of particular interest. Overall, parents reported a high degree of satisfaction with TPOL-D on all outcomes of interest.

Finally, Chapter 7 provides a general discussion of the research findings presented in this dissertation examining their contribution to the field, as well as the limitations of the research. Implications are discussed and suggestions made for future research.

Results from this thesis suggest that the developed intervention (TPOL-D) is a promising intervention for parents and carers of children with disabilities.

### **Declaration by author**

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

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## **Publications during candidature**

# Peer-reviewed papers

**Hinton, S.,** Sheffield, J., Sanders, M.R., & Sofronoff, K. (2017). A randomized controlled trial of a telehealth parenting intervention: A mixed-disability trial. *Research in Developmental Disabilities*. 65, 74-85. http://doi.org/10.1016/j.ridd.2017.04.005

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# **Publications included in the thesis**

**Hinton, S.,** Sheffield, S., Sanders, M.R., & Sofronoff, K. (2017). A randomized controlled trial of a telehealth parenting intervention: A mixed-disability trial. *Research in Developmental Disabilities*. 65, 74-85. http://doi.org/10.1016/j.ridd.2017.04.005 (**Chapter 5**)

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	Data collection and analysis (100%)
	Wrote the paper (100%)
Kate Sofronoff	Conception and design (15%)
	Critical revision of paper and
	provision of feedback (70%)
Jeanie Sheffield	Critical revision of paper and provision of feedback (20%)
Matthew Sanders	Conception and design (5%)
	Critical revision of paper and
	provision of feedback (10%)

#### **Contributions by others to the thesis**

My principal advisor Assoc. Professor Kate Sofronoff contributed towards the conceptualisation and design of the overall programme of research, as well as methodological advice and critical feedback on the written work. Dr Sofronoff also supervised therapists delivering interventions to the treatment as usual (TAU) control group in the randomised controlled trial, and provided editorial assistance with manuscripts being prepared for publication.

Dr Jeanie Sheffield provided advice re the statistical analysis plan for this dissertation, most particularly in relation to data analysis conducted in the randomised controlled trial (Chapter 5).

My secondary advisor Professor Matt Sanders contributed by providing advice towards the conceptualisation and design of research, as well as general advice around the methodology, statistical analyses, and reporting of results.

Statement of parts of the thesis submitted to qualify for the award of another degree

None

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# **Keywords**

telehealth, evidence-based parenting intervention, disability, behavioural family intervention, online, Triple P, Triple P Online – Disability, randomised controlled trial, web-based intervention, self-directed intervention

# **Australian and New Zealand Standard Research Classifications (ANZSRC)**

ANZSRC code: 170106, Health, Clinical and Counselling Psychology, 100%

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## **List of Abbreviations used in the thesis**

ABI: Acquired brain injury

AHT: Abusive head trauma

AI: Anxiety Inventory

ANOVA: Analysis of variance

ANZCTR: Australian New Zealand Clinical Trials Registry

ASD: Autism spectrum disorder

BFIs: Behavioural Family Interventions

BRIEF: Behavior Rating inventory of Executive Functioning

CAPES-DD: Child Adjustment and Parent Efficacy Scale – Developmental Disability

**CAPS:** Counselor Assisted Problem Solving

CBCL: Child Behavior Checklist

CBT: Cognitive behavioural therapy

CDI: Child Depression Inventory

CES-D: Centre for Epidemiologic Studies Depression Scale

CONSORT: CONsolidated Standards of Reporting Trials

CP: Cerebral palsy

CSES: Caregiver Self-Efficacy Scale

CSQ: Client Satisfaction Questionnaire

DBC-P: Developmental Behaviour Checklist – Primary Carer version

DD: Developmental delay

DNR: Did not respond

DS: Down syndrome

ECBI: Eyberg Child Behavior Inventory

ES: Effect size

FBII: Family Burden of Injury Inventory

FASD: Foetal alcohol spectrum disorder

FPS: online Family Problem Solving

GSI: Global Severity Index of the Symptom Checklist-90-Revised

HCSBS: Home and Community Social Behavior Scales

II: Intellectual impairment

I-InTERACT: Internet-based IN-teracting Together Everyday: Recovery After Childhood Traumatic Brain Injury

KS: Kate Sofronoff

LD/D: Language delay/Language disorder

PAFAS: Parenting and Family Adjustment Scale

PCIT: Parent-Child Interaction Therapy

PSI: Parenting Stress Index

OGCD: Other genetic/chromosome disorder

RCT: Randomised controlled trial

SD: Standard deviation

SH: Sharon Hinton

SPD: Sensory processing disorder

SSTP: Stepping Stones Triple P

STROBE: Strengthening the Reporting of Observational studies in Epidemiology

T1: Time 1 (pre-intervention assessment)

T2: Time 2 (post-intervention assessment)

T3: Time 3 (follow-up assessment)

TAU: Treatment as usual

TBI: Traumatic brain injury

Triple P: Triple P – Positive Parenting Program

TPOL: Triple P – Positive Parenting Program Online

TPOL-D: Triple P Online – Disability

VI: Vision impaired

WAI-SR: Working Alliance Inventory – Short Revised

#### Chapter 1

# Telehealth parenting interventions: An overview of the field and current research questions

Online and, more broadly, telehealth parenting interventions offer great potential for alleviating the burden of caring by providing 'anytime, anywhere' assistance and support to any parent or carer who has Internet access, coupled with a basic level of Internet knowledge and expertise (Dittman, Farruggia, Palmer, Sanders, & Keown, 2014; Sanders, Baker, & Turner, 2012). Defined for the purpose of the current research as the 'remote delivery of an intervention via telecommunication or digital delivery methods', telehealth interventions have emerged over the past three decades to encompass a broad range of technology-assisted communcation and treatment approaches, ranging from simple, web-based content pages and self-help sites through to online professional-led support groups and comprehensive, personalised, interactive interventions, with or without additional therapist support (Barak & Grohol, 2011).

Driving the growth in telehealth interventions is the dual promise of increasing population 'reach' (i.e., overcoming many of the common barriers to in-person access) while decreasing delivery costs (Baker & Sanders, 2016; Hall & Bierman, 2015; Jones et al., 2013; Macdonell & Prinz, 2016). Despite the acknowledged potential of these emerging telehealth technologies, and the proliferation of teleheath interventions more broadly, there remain few empirically-validated parenting programmes currently available in an online or telehealth delivery modality (Baker & Sanders, 2016). This suggests that interventions that target, and/or include, adaptations to meet the specific needs of parents and caregivers of children with a disability are likely be even more limited in availability.

It is well established that children with disabilities are at increased risk of experiencing behavioural problems compared with typically developing children, (Baker et al., 2003; Emerson, 2003; Roberts, Reid, Taylor, & Mazzucchelli, 2003; Sofronoff, Jahnel, & Sanders, 2011) while parents and caregivers of children with disabilities experience more stress, worry and depression (Einfeld, Tonge, & Clarke, 2013; Herring et al., 2006; Hudson & Gavidia-Payne, 2002; Stuttard et al., 2014). An early epidemiological study conducted by Rutter, Tizard, Yule, Graham and Whitmore (1976) suggested that children with intellectual disability are three- to four- times more likely to evidence behavioural and emotional problems than their non-disabled peers. In an Australian study, Einfeld and Tonge (1996) found that 40.7% of children with intellectual disabilities had severe behavioural or emotional problems using the Developmental Behaviour

Checklist (DBC; Einfeld & Tonge, 1992). Left untreated, behavioural and emotional problems are likely to persist across time (Einfeld et al., 2006; Sofronoff et al., 2011).

For the majority of children, parents will be the most immediate and influential factor in their environment (Hudson & Gavidia-Payne, 2002; Kaminski, Valle, Filene, & Boyle, 2008; Patterson, Chamberlain & Reid, 1982). With the growing consensus that a child's development, emotional functioning, language, social skills and future life opportunities will be substantially impacted by the quality of parenting they receive (Sanders & Kirby, 2012; Stack, Serbin, Enns, Ruttle, & Barrieau, 2010) it is unsurprising that parent training has become a common route to improving parenting skills (Sanders, Kirby, Tellegen, & Day, 2014). The fundamental premise of parent training is that modifying and/or enhancing parenting function will result in long-lasting and desirable change for both children and parents (Lundahl, Risser, & Lovejoy, 2006). Accordingly, parent training aims to teach parents to modify parenting practices and the family environment in a way that positively influences child behaviour and development (Kazdin, 1997). Acknowledged as the 'gold standard' for the treatment and prevention of child behavioural and emotional problems (United Nations, 2009; World Health Organisation, 2009), parenting programmes based on social learning and cognitive-behavioural principles have been found to be particularly effective in reducing problem behaviours in children and adolescents (Dretzke et al., 2009; Lundahl et al., 2006) with those that also incorporate 'live' coaching of skills being associated with even further gains in parenting skills, as well as greater reductions in child problem behaviours (Kaminski et al., 2008).

#### **Current research directions**

With strong support for the efficacy of evidence-based parenting interventions in improving child outcomes in both typically-developing children (Dretzke et al., 2009; Gardner, Hutchings, Bywater, & Whitaker, 2010; Kaminski et al., 2008; Kazdin, 2005; Lundahl et al., 2006) and (to a more limited extent) children with a disability (Einfeld et al., 2013; Hudson & Gavidia-Payne, 2002; Plant & Sanders, 2007; Roberts et al., 2003; Roux, Sofronoff, & Sanders, 2013) programmes that enhance parents' self-sufficiency in managing their children's behaviour and environment have become a common route for early intervention (Tellegen & Sanders, 2013). Despite the growing availability of evidence-based parenting interventions, research suggests that many parents who might benefit from such programmes do not access them (Baker & Sanders, 2016; Breitenstein, Gross, & Christophersen, 2014; Douma, Dekker, & Koot, 2006; Gross et al., 2011) with a number of logistical and personal barriers (such as cost, work, access to appropriate carers, perceived social stigma and so on) challenging participation in these traditionally 'face-to-face' interventions (Daneback & Plantin, 2008; Gega, Marks, & Mataix-Cols, 2004; Nieuwboer, Fukkink, &

Hermanns., 2013a). For parents of children with a disability, such barriers to participation are likely to be even further exacerbated by the very specific needs of their child.

While technology-assisted communications appear to offer great potential for overcoming many of the common barriers to participation reported with respect to in-person parenting programmes (Baker & Sanders, 2016; Hall & Bierman, 2015), evidence-based support remains limited. Of the handful of empirical trials that have been conducted in this area, the majority target parents of typically developing children (Day, 2016; Enebrink, Högström, Forster, & Ghaderi, 2012; Nieuwboer et al., 2013a; Sanders et al., 2012) leaving only a few that specifically target, and/or include, adaptations to meet the particular needs of parents and caregivers of children with a disability (Antonini et al., 2014; Kable, Coles, Strickland, & Taddeo, 2012; Wade, Karver, et al., 2014; Wainer & Ingersoll, 2015). Acknowledging the unique challenges faced by parents and carers of children with a disability, and the significant and continuing impacts that may be experienced by the parent, child, family and broader community when there is a failure to link these families to effective and appropriate supports, it is suggested there is an urgent need for the development of empirically-validated telehealth interventions created specifically for parents and carers of children with a disability

#### Aims and overview of this thesis

The aim of the thesis is to develop and trial a telehealth intervention targeting parents of children with a range (i.e. mixed) of disabilities. By addressing a very small part of the research gap identified, ultimately the goal is to extend knowledge and understanding of how telehealth parenting interventions can best support families that include children with disability. Chapters 2, 3, and 6 of this thesis are included as modified versions of manuscripts currently being prepared for submission as publications. Modifications have been undertaken where necessary to suit the flow and narrative of this thesis, but otherwise follow typical conventions for reporting empirical trials, with background, methodology, results and conclusions presented in each. Chapter 5 of this thesis consists of a paper in press in the peer-reviewed journal, Research and Developmental Disabilities.

After providing a brief introduction to the field of research in Chapter 1, Chapter 2 provides a systematic review undertaken between October 2013 and April 2014. This review highlighted the paucity of research available in relation to telehealth interventions specifically targeting parents of children with a disability, establishing the clear need for further research in this area. Notably, of those interventions that met criteria, all targeted specific disability areas such as acquired brain injury (ABI), traumatic brain injury (TBI) and Foetal alcohol spectrum disorder (FASD). Therefore, the current research, with its focus on a programme effective for use with parents of children with 'mixed disabilities', would be unique in the literature.

Chapter 3 details a qualitative inquiry as to the telehealth-related consumer preferences of parents and carers of children (aged 0-17 years) with mixed disabilities. The survey investigated parents' access to and use of the internet, degree of comfort with a range of online and telehealth-based technologies, the acceptability of online parenting training to this population and preferences in relation to potential delivery modalities and supports. Results were used to inform the development of a novel, telehealth-based parenting intervention for this population, including the nature and modality of resources used in support of the web-based interface.

Chapter 4 provides the protocol of a randomised controlled trial (RCT) of a telehealth-based parenting intervention for parents and carers of children (aged 2-12 years) with a disability. The theoretical basis, study hypotheses, methods and planned analyses for this protocol are described.

Chapter 5 consists of a published paper, which details the results of the RCT conducted on primary (child behavioural and emotional outcomes, and parenting skills and self-efficacy) and secondary outcomes (parent satisfaction with the intervention). Ninety-eight parents were randomly assigned to either the telehealth intervention (Triple P Online-Disability) or a treatment as usual control condition (care as usual over 8 weeks). At post-intervention parents receiving the TPOL-D intervention demonstrated significant improvements in parenting self-efficacy, parenting style, parental adjustment and family relationships, but not on child behavioural or emotional problems. At 3-month follow up intervention gains were maintained and/or enhanced. A significant decrease in parent-reported child behavioural and emotional problems was also detected.

Chapter 6 explores the acceptability of and parental satisfaction with TPOL-D. More specifically, research questions addressed: (1) intervention adherence; (2) overall satisfaction with TPOL-D; (3) therapist identification and alliance; (4) perceived helpfulness of the individual components of TPOL-D; (5) 'useability' of online modules; and (6) future consumer preference and advocacy issues. Completing parents in the intervention group reported high levels of satisfaction with TPOL-D.

Finally, Chapter 7 provides a discussion of the overall findings of the research, including an interpretation of the findings, limitations, and recommendations for future research. Clinical implications for delivery within a minimally sufficient framework are also briefly discussed.

#### Chapter 2

A systematic review of an online parent-training programme for parents of children with a disability

Online parenting interventions offer the potential of helping to alleviate the burden of caring by providing 'anytime, anywhere' assistance to a parent or carer who has Internet access, predicated upon a basic level of Internet knowledge and expertise (Dittman et al., 2014). With strong support for the efficacy of parenting interventions in improving child outcomes in both typically-developing children and children with a disability, programmes that enhance parents' self-sufficiency in managing their children's behaviour and environment are a common route for early intervention (Kaminski et al., 2008; Roberts, Mazzucchelli, Studman, & Sanders, 2006; Tellegen & Sanders, 2013). Despite these findings, there are few empirically-validated parenting programmes available in an online delivery modality, and even fewer programmes that specifically target, and/or include, adaptations to meet the specific needs of parents and caregivers of children with a disability.

The quality of parenting a child receives has a substantial impact on their development, emotional functioning, language, social skills and future life opportunities (Sanders & Kirby, 2012; Stack et al., 2010). Parenting programmes aim to teach parents to modify parenting practices and the family environment in order to influence child behaviour and development (Kazdin, 1997). Positive parenting programmes based on social learning and cognitive-behavioural principals have been found to be particularly effective in reducing problem behaviours in children and adolescents, with those that also incorporate 'live' coaching of skills being associated with even further gains in parenting skills, as well as greater reductions in child problem behaviours (Kaminski et al., 2008). Reviews of parenting interventions for children with developmental delay and disability, although more limited, have shown similar positive results (Hudson & Gavidia-Payne, 2002; Roberts et al., 2003; Tellegen & Sanders, 2013).

Children with developmental disabilities are at increased risk of experiencing more emotional and behavioural problems then their typically developing peers, whilst parents and caregivers of children with disabilities experience more stress, worry and depression (Cuijpers, 1999; Einfeld & Tonge, 1996; Herring et al., 2006; Skotarczak & Lee, 2015). Having both special needs and being at risk of increased burden, tailored parenting support is required for these families (Sofronoff et al., 2011). Unforunately, only a very small

percentage of parents of child with a disability access parenting advice (Douma et al., 2006). With regular attendance at face-to-face parenting programmes undoubtedly presenting a challenge for any parent, for parents of a child with a disability barriers to accessing such programmes are likely to be exacerbated by the special needs of their child (Roux et al., 2013).

The Internet and its various communication tools (such as web-based information pages, online noticeboards and social media forums) offers accessible and flexible forms of online communication through which professionals may readily disseminate current knowledge and offer tailored advice in either a synchronous or dyssynchronous manner, potentially enabling parents who would otherwise have great difficulty in attending in-person programmes to gain access (Antonini, Raj, Oberjohn, & Wade, 2012). Comparisons of online interventions with conventional face-to-face therapy have not only shown similar outcomes in treatment results, but have also indicated that online programmes do deliver parenting support in a manner that overcomes many of the traditional barriers to treatment access such as cost, childcare restrictions, perceived social stigma and so on (Daneback & Plantin, 2008; Enebrink et al., 2012; Mytton, Ingram, Manns, & Thomas, 2014; Nieuwboer et al., 2013a). While online parenting support remains a relatively novel field of study, one of the most obvious advantages of using the Internet to deliver parenting programmes is the diversity of population groups that can be targeted, with little regard to geographical barriers (Jennett et al., 2003).

Undertaken between October 2013 and April 2014, the purpose of the current systematic review was to identify and review evidence for the use of online inventions to provide training and education to parents and carers of children (aged 0 – 17 years) with a disability. Given the established effectiveness of parent training programmes targeting both the general population, and families of children with disabilities (Kaminski et al., 2008; Sanders et al., 2014; Stuttard et al., 2014; Taylor & Biglan, 1998; Tellegen & Sanders, 2013) the two main research questions of interest were:

Do online programmes specifically targeting parents of a child with a disability improve:

- 1) Child behaviour and emotional outcomes?
- 2) Parental skills, adjustment and confidence?

A secondary aim of the review was to identify and evaluate any available information concerning programme acceptability and satisfaction and/or the features that contribute to the effectiveness of such programmes.

#### Method

# **Search strategy**

The initial search strategy was developed by identifying the key words for the population and interventions of interest. A systematic literature search was conducted of seven electronic databases (CINAHL, Cochrane Library, EMBASE, MEDLINE, PsycINFO, PubMed and Web of Science) for the period from January 1990 – February 2014.

Where relevant, the searches used exploded Medical Subject Headings (MeSH) terms, and the following key words (with syntax adjusted as necessary for individual databases):

- 1. Intellectual Disabilit\* or Developmental Dela\* or Disabilit\* or Mental Retardation or Autis\* or Autistic Disorder\* or Asperger\* or Blind\* or Deaf or Hearing Disorder\* or TBI or Brain Injury\* or Foetal Alcohol Syndrome or FASD and
  - 2. Paediatric or pediatric or child or child\* and
- 3. Parent\* training or parent\* programme\* or parent\* intervention or parent\* support or parent\* psychoeducation or parent\* education or parent\* effectiveness training or behavior\* family intervention or behaviour\* family intervention or family therapy or family intervention or family support or family life education or behavior\* analysis or behaviour\* analysis or functional analysis or family program or family programme or behavior\* therapy or behaviour\* therapy or functional assessment or behaviour\* support or behavior\* support or behavior\* management or behaviour\* management or parent\* education and
- 4. Behaviour\* or behavior\* or function\* or stress or parent\* style or parent\* skill or parent\* behaviour or parent\* behavior or parent\* attitude or anxiety or depression or child behaviour or child behavior or emotion\* or suffering or depressive symptom\* or anxiety symptom\* or depressive disorder\* or anxiety disorder\* or behavioural symptom\* or behavioral symptom\* or parent\* efficacy or parent\* self-concept or parent\* adjustment and
- 5. Online or world wide web or web\* or telemedicine or computer-assisted instruction or telecommunication or telehealth or tele-health or Internet\* or distance

education or computer\* or Skype or social media or Facebook or blog or online group or distan\* or remote or virtual.

Thirteen additional papers were located by conducting library catalogue searches and reviewing additional references in the obtained studies.

Articles were restricted to those published in English and which used human subjects only. Results were initially restricted to randomised control trials (RCTs) involving parents of children with a disability aged from 2-12 years, however this approach failed to yield any results. In order to examine any available research with this specific target population and mode of delivery, the criterion were broadened both in relation to age (0-17 years) and research design (RCTs, quasi-RCTs, controlled trials, pre-post designs and case studies).

#### Inclusion and exclusion criteria

The inclusion criteria for this review required studies to meet the following:

- 1. Participants were parents and caregivers of children (aged 0 17 years) with a disability.
- 2. The intervention was an online-delivery parenting intervention including any programme that taught any manner of parenting problem-solving skills. Whilst programmes involving additional supports (e.g. telephone contact, in-person counsellor contact etc.) were included, the core parent-training programme was required to be delivered via web-based information pages.
- 3. The study delivered a global parenting programme rather than a single-skill training programme (such as word acquisition, toilet training etc.).
- 4. The study measured child behavioural and/or emotional outcomes and/or assessed parenting style or skill and/or parental coping and adjustment. Additionally, the tools of assessment were required to be either direct observation of frequency of behaviour or standardised parent- or child-report measures. Studies were not excluded if they involved the participation of the child or other family members (e.g. siblings).

Sources were excluded from the study if they:

1. Involved interventions that provided disability-related education alone, employed therapists working with children only or solely targeted the parent's own

psychological well-being (i.e. studies did not involve training parents in parenting skills).

- 2. Did not provide any/adequate measures of child behavioural or emotional outcome.
- 3. Assessed only the child's attainment of a skill, language or cognitive outcomes.
- 4. Focused primarily on child training with accompanying support for the broader family.

#### **Study selection**

Exclusion decisions were initially made based on the title and abstract, as assessed by two independent reviewers (SH and KS). After screening for duplicates, 916 papers were located of which all but 23 were rejected, post title and abstract screening, as failing to meet the criteria for the target population. Following a full text review, a further 17 papers were rejected. Two additional articles were identified by saved search engine protocols (April 2014), bringing the final review to eight articles.

#### **Data extraction**

Data extracted from each study included study design, nature, participant demographics, and (where available) programme title of online intervention. The first reviewer (SH) extracted data on relevant outcome measures, with queries clarified by the second reviewer (KS). Where results were available for individualised subscales as well as the global scale of a standardised measure, all scores were collected to retain the maximum amount of information.

#### **Data analysis**

To provide a measure of intervention effect size (ES), quantitative analysis was undertaken on the relevant outcome data from each study. For RCTs, the standardised mean difference was calculated with post-intervention scores for treatment and control groups by using Cohen's d, (refer 'equation 1'). For pre-post studies, the pre-group mean was subtracted from the post-group mean and divided by the standard deviation at pre-test, as illustrated in 'equation 2' (Lipsey & Wilson, 2001). Where decreases in the scores of a measure reflected improvement, effect measures were multiplied by '- 1' to ensure that all

effect sizes were consistent in direction. Effect sizes were classified according to Cohen's guidelines (Cohen, 1992) as small (0.2), medium (0.5) and large (0.8).

$$d = \underline{Mean_1 - Mean_2}$$
$$SD_{pooled}$$

(equation 1)

$$\underline{Mean_{post-test} - Mean_{pre-test}}$$
  
 $SD_{pre-test}$ 

(equation 2)

While it was the author's original intention to conduct a meta-analysis of collated outcome data, this was not undertaken for the following reasons: (i) half of the included studies were pre-post designs and their inclusion in a meta-analysis would have been questionable based on their potential for bias; (ii) there was substantial variation in the measures used and outcomes assessed; (iii) there was substantial heterogeneity in study participants with all studies but one focusing either on pre-teen or post-teen children; (iv) all identified studies involved multi-component interventions, therefore a meta-analysis would have failed to answer the main research question of this review as regards the efficacy of online parenting interventions.

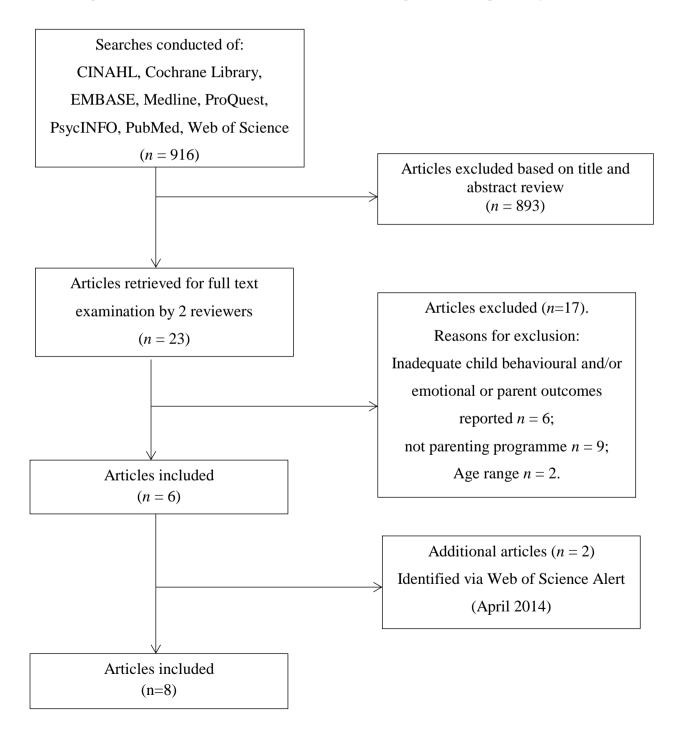
#### Results

#### **Description of studies**

The search strategy yielded 916 sources (see Figure 1). Of these, 893 articles were excluded as clearly not meeting inclusion criteria based on a review of the article's title and abstract. The remaining 23 articles were subject to a full text review, with six articles meeting inclusion criteria. Following the original search process, two additional articles were detected via a Web of Science search update (April 2014), bringing the final article total to eight. Of these, three involved RCTs (reported across five articles) and two involved case-series studies (reported across three articles).

In all three RCT studies, those in the comparison condition received a lower intensity intervention rather than no intervention at all. In one study (Kable et al., 2012), all

participants received a hard copy resource package containing information in relation diagnosis, neurodevelopmental consequences and links to various community and information services. In the other two studies – as reported across four papers – (Wade, Carey, & Wolfe, 2006a, 2006b; Wade, Karver, et al., 2014; Wade, Stancin, et al., 2014) participants were provided with access to a web-based homepage of links and resources, but were unable to access session content from the online intervention (online Family Problem Solving (FPS) and Counsellor Assisted Problem Solving (CAPS) respectively).



**Figure 2.1.** Flowchart of the systematic review search strategy

#### **Participant characteristics**

As detailed in Table 2.1, all participants were parents or caregivers of a child with a disability. Seven of the articles reported on studies undertaken with parents/caregivers of children with traumatic brain injury (TBI), with the one remaining article (Kable et al., 2012) focusing on parents/caregivers of children with Foetal alcohol spectrum disorder (FASD). Studies tended to concentrate either on pre-teen or post teen-aged children, with only one study – reported across two articles – (Wade, Wolfe, Brown, & Pestian, 2005a, 2005b) spanning a broader age demographic.

All studies targeted a heterogeneous caregiver group composed or parents, spouses or other close family members.

#### Characteristics of online interventions

As outlined in Table 2.1, all studies used web-based information pages as a central component of the intervention, with only one other online communication method being employed (i.e. synchronous videoconferencing). In only one of the included studies (Kable et al., 2012) were no additional online supports to the information pages provided. All studies included a component of parent training in behaviour management and all therapeutic contact was conducted by registered clinical psychologists or graduate students in clinical psychology. Four of five studies related to parents and caregivers of children with TBI, with the outstanding study (Kable et al., 2012) focusing on parents of children with FASD.

# **Types of intervention**

In a RCT design, Kable et al., (2012) employed two experimental groups to deliver parent education designed to improve the functioning of children with FASD. The first treatment group involved a series of two, in-person workshops (Workshop group) whilst the second intervention group accessed the programme via Internet-based information pages (Internet group). Both experimental formats were focused on delivering parent education to assess impact on the functioning of children with FASD.

In a pre-post design, based on Parent-Child Interaction Therapy (PCIT; Fernandez & Eyberg, 2009) and involving a comprehensive parent training programme including psychoeducation, live observation and in-vivo coaching of parenting skills over web-based video links, Wade, Oberjohn, Burkhardt, and Greenberg (2009) trialled the Internet-based INteracting Together Everyday, Recovery After Childhood Traumatic Brain Injury (I-InTERACT) programme. Sessions were accessed via the website homepage, and a small

cohort (n = 9) of pre-teen children and their caregivers completed 10 'core' web-based sessions (including training in positive parenting skills and cognitive-behavioural consequences of TBI) and up to four (of five) supplementary sessions based on the individual needs of the family. After completion of the self-guided web session each caregiver met with the therapist via videoconference – an interaction that also incorporated the in-vivo coaching component of the parenting skills training.

The remaining three studies (reported across six papers – (Wade et al., 2006a, 2006b; Wade, Karver, et al., 2014; Wade, Stancin, et al., 2014; Wade et al., 2005a, 2005b) investigated variants of a family problem solving approach. In all three studies, the parents/caregivers, child with TBI, and their school-aged siblings were invited to participate in the intervention, with the outcomes for parents/caregivers and children with TBI being published in separate articles (i.e. three studies reported over six articles).

In the earliest pre-post study (online Family Problem Solving (FPS): Wade et al., 2005a, 2005b), participants completed eight 'core' web-based sessions providing problem-solving, communication and TBI-specific problem behaviour management skills, plus an additional four sessions addressing the stressors and burdens placed on individual families. A synchronous online appointment with a therapist via videoconference formed the second part of each session.

In the two later RCTS (online Family Problem Solving (FPS): Wade et al., 2006a, 2006b) and (Counselor Assisted Problem Solving (CAPS): Wade, Karver, et al., 2014, Wade, Stancin, et al., 2014) participants again completed eight web-based 'core' sessions of similar content to the earlier pre-post study (Wade et al., 2005a, 2005b). In the earlier of these (Wade et al., 2006a, 2006b) parents accessed up to four (of six) supplementary sessions while in the later (Wade, Karver, et al., 2014, Wade, Stancin, et al., 2014) parents accessed up to four (of eight) supplementary sessions. Supplementary sessions access was offered based on the individual needs of participating families. A synchronous online appointment with a therapist formed the second part of each session for the earlier RCT (Wade et al., 2006a, 2006b). In the later study (Wade, Karver, et al., 2014, Wade, Stancin, et al., 2014), therapist contact with families via videoconference was scheduled bi-weekly for the first 3 months of the intervention (i.e. 6 videoconference sessions over 3 months). Additionally, up to four supplementary videoconference sessions could also be accessed (over months 4 and 5), again, as based on the individual family needs identified. All families were scheduled to participate in a final 'wrap up' videoconference session with the therapist in month 6.

 Table 2.1. Description of participants, study design and child disability

Study	Design	Disability	Intervention Name	Child Age (M & SD where available)	Parent/ Caregiver 'n' analysed	Control	Intervention Participants
Kable et al., 2012	RCT	FASD	Not specified	Rx1 7.34 (2.7) Rx2 6.72 (3.4) Ctrl 6.17 (2.9)	Rx1 = 18 Rx2 = 16 Ctrl = 16	FASD information package.	Parent/caregiver
Wade et al. (2005a, 2005b)	Pre-Post	ТВІ	online Family Problem Solving (FPS	M = 9.4yrs (age range $6.8 - 15.9$ )	8	N/A	Caregiver + child with TBI (+ school-aged siblings).
Wade et al. (2006a, 2006b)	RCT	TBI	online Family Problem Solving (FPS)	Rx 10.92 (2.45) Ctrl 11 (3.93)	Rx = 20 $Ctrl = 20$	Treatment as usual plus web page brain injury resources/links	Caregiver + child with TBI (+ school-aged siblings).
Wade et al. (2009)	Pre- Post	TBI	Internet-based IN- teracting Together Everyday, Recovery After Childhood TBI (I-InTERACT)	M = 6.5yrs (range 4.8 - 8.4)	6-11 (analyses conducted over time)	N/A	Caregiver + child with TBI.
Wade, Karver, et al., (2014) Wade, Stancin, et al., (2014)	RCT	ТВІ	Counselor Assisted Problem Solving (CAPS)	Age range 12-17	Rx = 57 $Ctrl = 61$	Home page of brain injury resources and links.	Caregiver + child with TBI (+ school-aged siblings).

#### **Outcomes investigated**

All five studies (as reported across eight articles) used standardised parent-reported measures of child behaviour. Measures assessed global child behaviour, as well as more specific measures of cognition, emotional and behavioural adjustment such as depression, social competence and antisocial behaviour. One study (Wade et al., 2005a, 2005b) also provided child-reported measures of depression and parent and child reports on parent-child interaction and school conflict. All but one study (Kable et al., 2012), used standardised measures to report on changes in parental adjustment, with one study (Wade et al., 2009) objectively measuring parenting skills and behaviours through blinded observers' ratings of parenting skills and parent-child interactions. Kable et al., (2012) also reported on gains in parental advocacy and behavioural regulation knowledge regarding their child's specific disorder. The majority of studies measured some aspect of caregiver satisfaction with the online intervention and/or technology, including whether parents would recommend the intervention to others and the overall helpfulness and value of the online intervention.

Although some studies reported on additional variables (such as parent-therapist therapeutic alliance, parent problem-solving skill, parent/caregiver prior use of technology and child-report on ease of use of website and videoconference), these have not been reported because they are considered to fall outside of the scope of the current review (Wade et al., 2005a, 2005b; Wade et al., 2006a, 2006b; Kable et al., 2012).

All included studies used a pre-post design, measuring outcomes only at completion of the intervention (or near intervention completion) without any further follow up. To equate time between baseline and post-intervention assessments in one study (reported across two papers – Wade, Karver, et al., 2014, Wade, Stancin, et al., 2014) follow-ups were scheduled without knowledge of whether the participant had completed the treatment protocol. Whilst it is reported that a subset of families did not receive the full course of treatment at the six-month follow up, it is not reported how many families this affected.

## **Qualitative assessment**

As detailed in Table 2.2, a commonly used, three-item, five-point scale (Jadad et al., 1996) was used to rate the quality of the three included RCT studies. The maximum score possible for the scale is five (comprising two points for descriptions of randomisation, two points for descriptions of double blinding, and one point for descriptions of withdrawals). No minimum score was set for inclusion of a study in the review. Two studies achieved a score

of three points and one of one point. None of the included studies used double-blinded masking to group allocation, resulting in loss of points due to the increased risk of bias. In relation to this 'blinding' criteria however, it should be noted that blinding is often difficult to achieve in psychological interventions due to ethical and practical concerns — and perhaps even more so (from a practical perspective) when the intervention involves a novel medium such as the one explored in this review. A further source of potential bias for all RCT studies included was the lack of adequate intention-to-treat analyses reported, in that no study included data for all randomised participants in their analyses.

**Table 2.2.** Methodological quality assessment of included randomised control trials (RCTs) using the Jadad Scale<sup>a</sup> (Jadad et al., 1996)

Item					
Study	1 (Randomisation)	2 (Double Blinding)	3 (Withdrawals)	Total	
Kable et al. (2012)	1	0	0	1	
Wade et al. (2006a, 2006b)	1 + 1	0	1	3	
Wade et al. (2013, 2014)	1 + 1	0	1	3	

<sup>&</sup>lt;sup>a</sup> Scoring key - Scale of item score: Either give a score of 1 point for each 'yes' or 0 points for each 'no'. There are no in-between marks. Give 1 additional point if: For question 1, the method to generate the sequence of randomisation was described and it was appropriate (table of random numbers, computer generated, etc.) and/or If for question 2, the method of double blinding was described and it was appropriate (identical placebo, active placebo, dummy, etc.) Deduct 1 point if: For question 1, the method to generate the sequence of randomisation was described and it was inappropriate (patients were allocated alternately, or according to date of birth, hospital number, etc.) and/or for question 2, the study was described a s double blind but the method of blinding was inappropriate (e.g., comparison of table vs. injection with no double dummy).

(continues)

The two included pre-post studies were assessed (refer Table 2.3) using the Strobe Scoring System (Vandenbroucke et al., 2007), with scores of 17.6 and 21.8 obtained respectively. Across the two studies, areas of commonality that resulted in a loss of points included the omission of: (a) reporting of particular details from the study; (b) power analysis to determine sample size; and (c) explanation as to how missing data were addressed.

**Table 2.3.** Methodological quality assessment of included pre-post studies using the STROBE Statement (Vandenbroucke et al., 2007)

		Study		
Item	Criterion	Wade et al., (2005a, 2005b)	Wade et al., (2009)	
TITLE & ABSTRACT				
	Indicate the study's design with a commonly used term in the title or the abstract	0	0	
	1b. Provide in the abstract an informative and balanced summary of what was done and what was found	1	1	
INTRODUCTION				
Background/rationale	2. Explain the scientific background and rationale for the investigation being reported	1	1	
Objectives	3. State specific objectives, including any pre-specified hypotheses	1	1	
METHODS				
Study design	4. Present key elements of study design early in the paper	0	0	
Setting	5. Describe the setting, locations, and relevant dates: (0.2 points awarded to each of the following 5 components to a			
	maximum of 1)	0.2	0.2	
	<ul><li>a. Setting of sessions</li><li>b. Setting of assessment</li></ul>	0.2	0.2	
	c. Dates of recruitment	0	0.2	
	d. Location of recruitment	0.2	0.2	
	e. Specified when follow-up data collected	0.2	0.2	
Participants	6. Give the eligibility criteria, and the sources and methods of selection of participants	1	1	

Variables	7. Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers		
	a. Outcomes	1	1
	b. Exposures (0.33 points awarded to		
	each component to total maximum of 1):	0.22	0.22
	i. Number sessions.	0.33 0.33	0.33 0.33
	<ul><li>ii. Length of sessions.</li><li>iii. Frequency sessions.</li></ul>	0.33	0.33
	c. Effect modifiers, predictors, confounders	1	1
Data sources/ measurement	8. For each variable give sources of data and assessment methods	1	1
Bias	9. Describe any efforts to address potential sources of bias: (0.5 points awarded to each component to total maximum score of 1)		
	a. Independent raters	0	0.5
	b. Selection bias	0	0.5
Study size	10. Explain how the study size was arrived at	0	0
Quantitative variables	11. Explain how quantitative variables were handled in the analyses	1	1
Statistical methods	12a. Describe all statistical methods, including those used to control for confounding	0	1
	b. Describe any methods used to examine subgroups and interactions	N/A	0
	c. Explain how missing data were addressed	0	0
	d. If applicable, explain how loss to follow-up was addressed	N/A	1
	e. Describe any sensitivity analyses	N/A	N/A
RESULTS			
Participants	13a. Report numbers of individuals at each stage of study.	0	0
	b. Give reasons for nonparticipation at each stage	0	1
	c. Use of a flow diagram.	0	0
Descriptive data	14a. Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders)	1	1
	potential confounders). b. Indicate the Number of Participants with missing data for each variable of	0	0
	interest c. Cohort Study: summarise follow-up time e.g. average and total amount	0	0
			continues

Outcome data	15. Outcomes and exposures. Report numbers of outcome events or summary measures	1	1
Main results	16a. Give unadjusted estimates and their precision b. Report category boundaries when continuous variables were categorised	1 N/A	1 N/A
	c. If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A	N/A
Other analyses	Report other analyses done	0	1
Key results	Summarise key results with reference to study objectives	1	1
Limitations	(0.5 points awarded for each component to a maximum of 1):		
	Discuss limitations of the study, taking into account sources of potential bias or	0.5	0.5
	imprecision Discuss both direction and magnitude of any potential bias.	0.5	0.5
Interpretation	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	1	1
Generalisability	Discuss the generalisability of the study results	1	0
OTHER INFORMATION			
	Give the source of funding	1	1
TOTAL		17.6	21.8

## **Study findings**

Tables 2.4 and 2.5 present the findings for child behavioural/emotional and parent adjustment/skill outcomes for the three RCT studies and two pre-post studies, respectively. The effect sizes provided were calculated specifically for this review.

Table 2.4. Results of RCTs reporting on child and parent adjustment following intervention

			Treatment		Control	
Study	Outcome measure	n	Mean (SD)	n	Mean (SD)	ESa
Child Outcome						
Kable et al., (2012) <sup>b</sup>	CBCL: Behavior Problems (Total)	16	64.5 (3.5)	18	65.2 (3.4)	0.20
	CBCL: Internalizing	16	60.7 (3.3)	18	60.0 (3.3)	-0.21
	CBCL: Externalizing	16	64.3 (3.8)	18	64.3 (3.9)	0
Wade et al., (2006a)	CBCL: Behavior Problems (Total)	19	47.78 (11.43)	20	56.06 (11.82)	0.71
	CBCL: Internalizing	19	47.39 (10.30)	20	56.72 (12.42)	0.82
	CBCL: Externalizing	19	48.17 (10.68)	20	52.00 (11.02)	0.35
	HCSBS: Social Competence (Total)	19	53.15 (9.89)	20	45.50 (11.50)	0.71
	HCSBS Self-Mgt/Compliance <sup>c</sup>		52.35 (10.48)	20	45.50 (11.37)	0.63
	HCSBS Peer	19	53.55 (9.07)	20	46.50 (10.31)	0.72
Wade, Stancin, et al.,	CBCL: Externalizing	57	49.82 (11.53)	61	52.69 (11.28)	0.25
(2014)	CBCL: Internalizing	57	49.37 (12.13)	61	52.56 (11.60)	0.27
	CBCL Subscale: Aggressive	57	54.86 (8.45)	61	56.16 (8.78)	0.15
	CBCL Subscale: Attention	57	56.32 (6.79)	61	60.00 (10.18)	0.43
	CBCL Subscale: ADHD	57	55.98 (7.47)	61	58.51 (8.75)	0.31
	CBCL Subscale: Conduct	57	54.68 (7.57)	61	56.59 (7.66)	0.25
Parent Outcome						
Wade et al., (2006b)	GSI <sup>c</sup>	19	52.33 (10.69)	20	58.37 (11.49)	0.54
	CES-D <sup>c</sup>	19	9.25 (7.09)	20	18.15 (13.49)	0.83
	$AI^c$	19	9.25 (4.99)	20	14.05 (7.50)	0.75
Wade, Karver, et al.,	GSI <sup>c</sup>	57	47.52 (11.40)	61	53.83 (12.12)	0.54
(2014)	CES-D <sup>c</sup>	57	9.90 (8.36)	61	15.46 (11.72)	0.55
	CSES <sup>c</sup>	57	92.36 (6.93)	61	87.24 (10.76)	0.57

<sup>&</sup>lt;sup>a</sup> Effect sizes are those calculated specifically for this review.

Note: AI = Anxiety Inventory; CES-D = Centre for Epidemiologic Studies Depression Scale; CBCL = Child Behavior Checklist; CSES = Caregiver Self-Efficacy Scale; ES = effect size; HCSBS = Home and Community Social Behavior Scales; GSI = Global Severity Index of the Symptom Checklist-90, Revised.

<sup>&</sup>lt;sup>b</sup> Internet (Rx2) and Control group data only

 $<sup>^{</sup>c} p < .05$ 

<b>Table 2.5.</b> Results of pre-post studies reporting on child and parent adjustment following	
intervention	

Study	Outcome measure	n	Pre Mean (SD)	Post Mean (SD)	ESª
Child Outcome					
Wade et al., (2005b)	BRIEF-GEC	6	62.17(11.70)	54.83 (3.31)	0.63
	CDI	6	4.40 (4.16)	5.20 (5.36)	-0.19
	HCSBS-SC	6	43.83 (9.35)	48.33 (7.76)	0.48
	HCSBS-AB <sup>2</sup>	6	51.67 (7.50)	45.50 (6.74)	0.82
Wade et al., (2009)	ECBI: No. Behaviors	5	65.20 (7.80)	55.80 (8.90)	1.21
	ECBI: Behavior Intensity	5	60.50 (10.17)	56.92 (5.14)	0.34
<b>Parent Outcome</b>					
Wade et al., (2005a)	AI: Anxiety	8	14.38 (7.09)	11.88 (7.40)	0.35
	CES-D: Depression <sup>b</sup>	8	22.75 (10.98)	16.38 (11.16)	0.58
	FBII: Burden of Injury <sup>c</sup>	8	51.25 (25.04)	16.25 (8.17)	1.40
	PSI: Stress b	8	102.38 (22.88)	84.75 (27.02)	0.78
	$GSI^b$	8	63.63 (8.97)	57.00 (12.97)	0.74
Wade et al., (2009)	Obs: Total Positive Behb	6	3.09 (2.51)	17.29 (10.11)	5.66
	Obs: Total Negative Beh <sup>c</sup>	6	31.64 (10.58)	6.29 (5.31)	2.40

<sup>&</sup>lt;sup>a</sup> Effect sizes are those calculated specifically for this review

Note: AI = Anxiety Inventory; BRIEF = Behavior Rating inventory of Executive Functioning; CDI = Child Depression Inventory; CES-D = Centre for Epidemiologic Studies Depression Scale; ECBI = Eyberg Child Behavior Inventory; ES = effect size; FBII = Family Burden of Injury Inventory; HCSBS = Home and Community Social Behavior Scales; Obs = Observations via live Web camera; PSI = Parenting Stress Index; GSI = Global Severity Index of the Symptom Checklist-90-Revised.

#### Child behavioural and emotional outcomes

Measures of child behavioural and emotional outcomes were reported for all included studies. In the one intervention, focusing on caregivers of children with FASD (Kable et al., 2012), no significant change effects were found in the Internet treatment group for child behavioural outcomes (CBCL internalizing, externalizing or total).

In the TBI-related studies, three different web-based programmes were employed; online Family Problem Solving (FPS) (Wade et al., 2005a, 2005b; Wade et al., 2006a, 2006b); Internet-based IN-teracting Together Everyday, Recovery After Childhood Traumatic Brain Injury (I-InTERACT) (Wade et al., 2009); and Counselor Assisted Problem Solving (CAPS) (Wade, Karver, et al., 2014, Wade, Stancin, et al., 2014). Although the interventions shared similarities in delivery modality (online web pages with synchronous

<sup>&</sup>lt;sup>b</sup> Indicates significance p < .05

<sup>&</sup>lt;sup>c</sup> Indicates significance p < .01

videoconferencing), each had clear points of distinction and purpose (e.g. live coaching of parents, number and type of supplementary sessions, age of child with TBI).

Evidence for FPS was mixed across studies. In the earliest of the pre-post studies (Wade et al., 2005a, 2005b), FPS resulted in significant improvements in child antisocial behaviour, resulting in a large effect size, ES = 0.82. No other significant differences were found. In the later RCT study (Wade et al., 2006a, 2006b), a significant treatment effect for child self-management and compliance was reported, along with a moderate effect size of ES = 0.63. No other reported measures for child and behavioural outcomes reached significance. The authors also conducted a series of hierarchical regression analyses in order to determine whether family member or injury characteristics moderated treatment efficacy.

Improvements in parent-reported child behaviour outcomes were found to be significant for lower socio-economic status (SES) families, but not for higher SES families – suggesting that FPS therapy may be more beneficial in improving behaviour problems amongst individuals of lower SES (Wade et al., 2006a).

In a small, pre-post study investigating I-InTERACT (Wade et al., 2009), no significant differences were found for either the number or intensity of problem child behaviours reported. A trend for reductions in the number of problem behaviours was reported, with a corresponding large effect size ES = 1.12; however, no similar trend was found for behaviour intensity.

In the most recent and largest RCT study undertaken (Wade, Karver, et al., 2014, Wade, Stancin, et al., 2014), the efficacy of the CAPS intervention was examined across both the cohort as a whole, and based on the sample divided into high- (9<sup>th</sup> -12<sup>th</sup> grade) and middle-school (6<sup>th</sup>-8<sup>th</sup> grade) aged students. While no significant differences in child behavioural outcomes were detected in analyses conducted on the sample as a whole, it should be noted that when further analysis was undertaken at 'school level' (and after controlling for baseline symptoms) significantly lower levels of externalising symptoms, aggression, attention problems, ADHD and conduct disorder symptoms were found for the high-school aged group.

## Parenting skill and parenting adjustment

Two of the three RCT studies (Wade et al., 2006b; Wade, Karver, et al., 2014) reported on parent outcomes. Commonly-reported significant group effects included improvements in depression (ES = 0.83 and 0.55, respectively) and caregiver psychological

distress (ES = 0.54 and 0.54, respectively). Wade et al., (2006b) also found that parents undertaking the FPS reported significantly less anxiety (ES = 0.75), and Wade, Karver et al., (2014) found the CAPS intervention to have a significant improvement on caregiver self-efficacy (ES = 0.57).

In the pre-post study investigating FPS (Wade et al., 2005a), significant group effects were found for burden of injury (ES = 1.40), parenting stress, (ES = 0.78), depression (ES = 0.58) and general symptoms (ES = 0.74). Anxiety symptoms did not change significantly.

In the only study to include live observation by blinded assessors, Wade et al., (2009) it was found that parents completing the I-InTERACT programme reported significant prepost differences in positive parenting behaviours (ES = 5.66), whilst also finding significant decreases in problematic parenting behaviours (ES = 2.40).

## Parent satisfaction with online programmes

Four of the five included studies included some measure of reporting on parents' satisfaction with the programmes and/or technology used. In the earliest study undertaken by Wade et al., (2005a, 2005b), all parents, children with TBI and their siblings rated the FPS programme as very helpful, with all participants (excluding one child with TBI) also indicating that they would recommend the programme to others. Similar results were found in the later trials of the FPS programme (Wade et al., 2006a, 2006b) and the I-InTERACT programme (Wade et al., 2009).

In the only included study to involve parents and caregivers of children with FASD (Kable et al., 2012), caregiver satisfaction with the programme was slightly less positive, with 82.4% of parents in the Internet-based intervention reporting 'overall satisfaction' and 76.5% of parents indicating that they would recommend the programme to others.

One of the included studies (reported in Wade et al. 2006b) explored whether participating parents believed a face-to-face intervention would have been preferable to the online intervention. Although all parents in this study (100%) did indicate they would recommend the programme to others, seven parents (33%) also indicated that they would prefer to meet with the therapist in person.

#### Discussion

A comprehensive search of the literature revealed a small number of studies (three RCTs and two pre-post studies) specifically focusing on online parenting programmes for

parents and carers of children with a disability aged 0-17 years. Although the present review does provide preliminary evidence of the efficacy of such programmes in this population, the small number of studies available, the restricted areas of disability investigated (TBI and FASD), and the fact that one researcher is the first author across four of the five included studies, indicates that this is currently a very limited field of research.

With respect to the two primary outcomes of interest, two of five studies – including one RCT (Wade et al., 2006a) and two pre-post studies (Wade et al., 2005b; Wade et al., 2009) demonstrated efficacy in improving at least one aspect of child or adolescent outcome, whilst 100% of studies that evaluated parental outcomes found significant improvements in parental adjustment and/or coping.

A secondary aim of the review was to identify and evaluate available outcome data on programme acceptability and satisfaction for parents and caregivers. Four of the five studies (Wade et al., 2005b; Wade et al., 2006b; Wade et al., 2009; Kable et al., 2012) incorporated some measure of reporting on parents' satisfaction with the programme, with favourable results as to online content, ease of use and the likeliness of parents to recommend the programme to others. Notably, in the one study in which parents were asked about their preferences for programme delivery (Wade et al., 2006b), approximately a third of the sample reported that they would have preferred to meet with the therapist in person, indicating that not all parents and caregivers are likely to be equally receptive to online programmes. This response would benefit from further exploration in future research.

Given the small number of papers identified, a major strength of the identified literature is the presence of RCTs. The most recent of these (Wade, Karver, et al., 2014, Wade, Stancin, et al., 2014) seem particularly promising given the large sample size obtained. The replication of positive results across a number of programme variations is also encouraging; however, caution is required in generalising the results to parenting programmes for children with other disabilities given that all but one study specifically focuses on one area of disability.

A recent analysis by Ekeland, Bowes, and Flottorp (2010) of the systematic reviews conducted in telemedicine noted that there is generally a lack of high quality evidence supporting the effectiveness of such programmes. Given the small sample sizes of the identified studies, the reliance on self-report parent measures (with the potential for social desirability biases) and the fact that only one study used independent observational data to evaluate parent and child outcomes this review reflects similar issues.

Also of note is that none of the identified studies undertook follow-up assessment beyond the immediate post-intervention period, making it impossible to determine whether treatment gains were maintained across time for any of the included studies and/or whether less intensive intervention programmes might lead to similar outcomes. Further, the studies identified by this review were composed of multiple components making it unclear exactly which component(s) of each study were the mechanisms for change. Given that five of the six reported studies involved therapist contact via synchronous videoconferencing, caution should also be exercised in attributing the significant outcomes achieved to the online content solely.

#### Conclusion

Despite the well-established empirical support for the efficacy of face-to-face parenting programmes for child behavioural problems in children with disabilities (Hudson & Gavidia-Payne, 2002; Taylor & Biglan, 1998; Tellegen & Sanders, 2013), as well as the acknowledged potential of the Internet for delivering parenting interventions in an accessible way (Dittman et al., 2014; Nieuwboer et al., 2013a) research into online (and more broadly telehealth) parenting programmes for parents of children with a disability remains very much in its infancy. Moving forward, there is significant scope for further high-quality RCTs that develop new, or adapt current, parenting programmes for evaluation with this population in an online delivery modality.

## Addendum to systematic review (Feb 2017)

To explore the growth in evidenced-based online parenting programmes since the original systematic review was undertaken, a further (non-systematic) review of the literature was undertaken for the period from January 2014 to February 2017. To maintain consistency, inclusion and exclusion criteria were applied as per the original by two authors (SH and KS). Only two additional RCTs (reported across three papers) meeting criteria, were detected in this period - with one of these involving a 'subset' of participants from the larger RCT. Table 2.6 provides an overview of these additional studies, including a description of the participants, study design and child disability.

While not a 'novel' study as such, it is also worth noting an additional study by Wade et al., (2015) detected during this update. Extending on the findings of an earlier study included in the original systematic review (CAPS: Wade, Karver, et al., 2014, Wade, Stancin, et al., 2014) this research examines the maintenance of treatment effects during the initial 12-

months post treatment completion (as well as the moderating effects of family socioeconomic status on treatment response) providing a valuable contribution to the literature.

**Table 2.6.** Description of participants, study design and child disability: Addendum review (April 2014 – February 2017)

Study	Design	Disability	Intervention Name	Child Age (M & SD where available)	Parent/Caregiver participants 'n' analysed	Control	Intervention participants
Antonini, et al., (2014) <sup>a</sup> Raj, Antonini, Oberjohn & Cassedy, (2015) <sup>a</sup>	RCT	TBI	I-InTERACT	Rx 5.60 (2.09) Ctrl 5.24 (2.14)	Rx 20 Ctrl 17	Internet Resource Comparison (IRC) Group	Parent/caregiver + child with TBI.
Mast et al., (2014) <sup>b</sup>	RCT	Abusive head trauma (AHT)	I-InTERACT	3 – 9 yrs at study enrolment.	Rx 4 Ctrl 3	Internet Resource Comparison (IRC) Group	Parent/caregiver + child with AHT

<sup>&</sup>lt;sup>a</sup> The results of the RCT are reported over two published studies.
<sup>b</sup> Participants in this study constituted a subset of participants from the Antonini et al., (2014) study. Children of participants had a TBI caused by abusive head trauma.

## Chapter 3

Assessing consumer preference in telehealth-based parent-training programmes

For families of children with a disability, problem behaviours such as tantrums, aggression and self-injury can be difficult to manage, emotionally distressing and disruptive to everyday routines and activities (Einfeld et al., 2013; Reichman, Corman, & Noonan, 2008; Roberts et al., 2003). Left untreated, behaviour problems may threaten the personal health, safety and well-being of the child as well as their inclusion in social, educational and community activities (Roberts et al., 2006; Roux et al., 2013; Stuttard et al., 2014). The many unique challenges faced by families of children with disability are likely to be exacerbated in the absence of effective and appropriate supports (Families Special Interest Research Group of IASSIDD, 2014).

While there is a strong evidence base to attest to the efficacy of parenting interventions in improving child and parent outcomes in both typically-developing children and children with a disability (Barkley, 2013; Baker & Sanders, 2016; Brown, Whittingham, Boyd, & McKinlay, 2014; Dretzke et al., 2009; Einfeld et al., 2013; Enebrink et al., 2012; Kazdin, 2005; Tellegen & Sanders, 2013), low participation rates at a population level remain a significant and ongoing challenge (Breitenstein et al., 2014; Sanders, Dittman, Farruggia, & Keown, 2014). One promising avenue for extending the reach of parenting programmes is through the development of more flexible modes of delivery, such as self-help and telehealth interventions (Enebrink et al., 2012; Ingersoll & Berger, 2015).

With its ever-increasing accessibility and flexible forms of communication, high speed broadband Internet allows practitioners to develop and deliver parenting interventions either in real-time (synchronous) and/or self-paced (asynchronous) environments, utilising a wide variety of interactive and multi-media experiences (Nieuwboer et al., 2013a). Although the controlled evidence remains limited, comparisons of telehealth parenting interventions (defined for the purpose of the current resarch as the remote delivery of an intervention via telecommunication or digital delivery methods) with conventional face-to-face therapy have not only shown comparable outcomes in treatment results but have also indicated that online programmes deliver parenting support in a manner that overcomes many of the traditional barriers to support, while maintaining high levels of client satisfaction (Day, 2016; Sanders et al., 2012; Wade et al, 2012). While research in relation to telehealth parenting interventions that specifically target, and/or include, adaptations to meet the specialised needs of parents and caregivers of children with a disability is even more limited, the evidence that

is available provides similar support to the efficacy of such interventions for improving parent skill and adjustment, as well as child behaviour outcomes, (Antonini et al., 2014; Kable et al., 2012; Pickard, Wainer, Bailey, & Ingersoll, 2016; Wade et al., 2015).

While acknowledging the promise of telehealth parenting interventions, increasing accessibility to effective parenting programmes using telehealth modalities remains of little utility if increased consumer uptake does not also occur. With the success of any parenting programme depending on both the willingness of parents to engage, as well as the feasibility of such engagement, it is vital that consumer preference be used to inform online parenting intervention design (Love, Sanders, Metzler, Prinz, & Kast, 2013; Macdonell & Prinz, 2016). To date, much of the research exploring determinants of parental engagement to parenting programmes has focused on factors that predict engagement in face-to-face and self-administered interventions (Metzler, Sanders, Rusby, & Crowley, 2012) with little research having been conducted on the factors associated with parents' interest in and willingness to utilise telehealth, such as prior technology use and comfort with technology (Carey, Wade, & Wolfe, 2008; Ingersoll & Berger, 2015).

With recent research in telehealth-based behavioural interventions indicating that even brief therapist support increases treatment adherence (Mohr, Cuijpers, & Lehman, 2011) as well as efficacy (Palmqvist, Carlbring, & Andersson, 2007; Spek et al., 2007) consumer preference as to the desirability of additional supports, most particularly therapist support, was considered a key area of inquiry for the current research.

Targeting the specific population of parents and carers of children (aged 0-17 years) with a disability, the purpose of the present research was to determine parent-consumer:

- 1) Internet usage and access.
- 2) Comfort with a range of telehealth tools.
- 3) Perceived acceptability of online parenting programmes.
- 4) Preferred additional support/s (if any) to online parenting programmes.

#### Method

The data presented within this paper was obtained from a survey constructed to investigate the utility and desirability of a novel telehealth intervention for the target population group of parents and carers of children with a disability. The survey targeted parents and carers of children (aged 0-17) with a disability. No limitation was placed on the nature of the child's disability. The survey contained 26 questions, of which none were forced response (refer Table 1). The survey was conducted between March and July 2014.

Recruitment was undertaken via a web-based survey link (SurveyMonkey) emailed to relevant support agencies on an Australia-wide basis, along with a request for dissemination assistance. Individual parents who made inquiries about completing an online parenting programme via the Stepping Stones Triple P Project website during this period were also emailed the link (<a href="http://www.triplep-steppingstones.net/au-en/stepping-stones-triple-p/the-stepping-stones-triple-p-project/">http://www.triplep-steppingstones.net/au-en/stepping-stones-triple-p/the-stepping-stones-triple-p-project/</a>). No reminders were sent and no follow-ups were undertaken post emailing of the link. Parents and carers could undertake the survey on an anonymous basis, and were informed their responses would be used in developing future programmes to meet the specific needs of parents of children with a disability. Respondents were also given the option to provide their name and contact details (Question 1) to be entered in a draw to win a \$100 gift card – provided as a small incentive for participating in the survey. In total, 121 surveys were returned, however only 101 responses were analysed as 20 responses were excluded for failing to meet the criteria of being a current parent or carer of a child with a disability who was aged between 0-17 years.

Ethical approval was obtained from the University of Queensland in accordance with National Health and Medical Research Council of Australia standards; ethics approval number 2012001065. Results are summarised and presented in a descriptive fashion. Where required, SPSS Version 24 (IBM Corp.) was used for any statistical analysis.

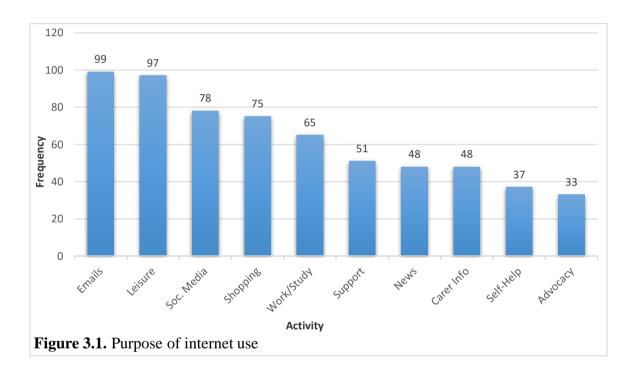
**Table 3.1.** Survey questions

	Question
1.	Name and contact details (Note: Only answered if parent wished to enter incentive draw).
2.	What is your gender?
3.	Which category below includes your age?
4.	Which of the following categories best describes your employment status?
5.	How many children (0-17 yrs) with a disability do you care for?
6.	What is the age(s) of the child(ren) that you care for?
7.	Which state/territory do you live in?
8.	Which of the following best describes the area you live in?
9.	Which of the following devices do you have at-home access to?
10.	Which of the following devices do you most often use to connect to the internet?
11.	How often do you access the internet?
12.	From which of the following locations do you regularly access the internet?
13.	For what purpose/s do you use the internet? Please select all responses that apply to you.
14.	How often do you log into social media networks (e.g. Facebook, Google+, etc.)?
15.	What forms of social media do you currently use?
16.	What forms of other online media do you currently use?
17.	Please rate how comfortable you are with using the following methods of communication:  Facebook private group Facebook private messaging Skype Jabber Teleconferencing Telephone call Online chat rooms Online noticeboards Text messaging
18.	What problems do you regularly experience when using the internet?
19.	Which of the following are personal barriers to using the internet?
20.	What do you think might be some of the benefits of accessing a parent training programme online?
21.	What do you think might be some of the drawbacks of undertaking a parent training programme online?
22.	Would you undertake a parent training programme online?
23.	If you were to undertake an online parenting programme, would you prefer (self-directed, self-directed + therapist contact, self-directed+ therapist contact + telehealth parent group).
24.	If you were to undertake an online parenting programme that included additional 'one-on-one' support with a therapist, in which ways would you be happy to receive that support?
25.	Following on from Question 23, which of the below options would be your FIRST PREFERENCE for receiving such 'one-on-one' support from a therapist?
26.	If you were to undertake an online parenting programme with additional online 'group' support with other parents, in which ways would you be happy to receive that support?

#### **Results**

Of the 101 eligible surveys received, 96% (n = 97) were fully completed. Where applicable, results indicate incomplete data through the provision of a denominator when nominating sample size. Table 3.2 shows the demographics of the survey respondents, including frequency of Internet use, access to home Internet and most common access device/s. The majority of respondents 97% (n = 97/100) used the Internet on at least a daily basis, with all respondents using the Internet at least weekly. All respondents (n = 101) indicated that they had access to the Internet from home.

Respondents were found to use the Internet for a broad range of purposes with the most popular service being email 98% (n = 99) (refer Figure 3.1).



**Table 3.2.** Survey respondent demographics

Variable		n	%
Sex			
	Female	91	90
	Male	10	10
Age			
	18-29	4	4%
	30-44	56	55%
	45-55	31	31%
	56-70	7	7%
	71 or older	1	1%
<b>a</b>	DNR <sup>a</sup>	2	2%
State	0 1 1		650/
	Queensland	66	65%
	Victoria	9 8	9%
	New South Wales Western Australia	8 14	8% 14%
	Tasmania	14	14% 1%
	DNR <sup>a</sup>	3	3%
Location	DINK	3	3 /0
Location	Urban	82	81%
	Rural	16	16%
	Remote	2	2%
	DNR <sup>a</sup>	1	1%
No of child	dren with a disability (aged 0-	-17vrs)	
110. 01 01111	One	73	72%
	Two or more	28	28%
Ago of chi		20	2070
Age of cili	ld(ren) with disability <sup>b</sup>		20/
	0-2	3	3%
	2-12	78 26	77%
	13-17	26	26%
	$DNR^a$	3	3%
Home inte			
	Yes	101	100%
_	No	0	0%
Frequency	of internet use		
	Multiple times daily	70	69%
	Daily	27	27%
	1-2 times per week	3	3%
	Less than once per week	0	0%
	DNR <sup>a</sup>	1	1%
Most frequ	ently used access device/s (m	ultiple respon	nse permitted) <sup>c</sup>
-	Smart phone	59	58%
	Laptop	43	42%
	Tablet	41	41%
	Desktop computer	35	35%
	Web-access TV	3	3%

<sup>&</sup>lt;sup>a</sup> DNR = Did not respond. <sup>b</sup> Reported n is > 101 due to parents with multiple children with disabilities. <sup>c</sup> Reported n is > 101 as multiple responses permitted.

When asked to rate their 'degree of comfort' from 1 (Do not use) to 7 (Extremely comfortable) with a range of telecommunication tools (other than email), text messaging ( $\bar{x}$  = 6.37) and telephone call ( $\bar{x}$  = 6.09) were identified as tools of higher comfort (refer Table 3.3).

Eighty-nine percent (n = 88/99) of respondents indicated that they would undertake an online parenting programme, flagging a high degree of acceptability for this modality within the respondent group. Of the 11 'declining' parents, 100% reported regular use of the internet (i.e., of at least daily frequency), negating access as being the major deterrent to engagement. Lack of face-to-face contact (n = 7/11), inability to ask questions (n = 6/11) and inability to meet other parents/therapist (n = 5/11) were reported as being of concern, however. Parents who indicated that they would undertake an online parenting programme, also indicated a strong preference for the inclusion of additional telehealth supports to accompany the online parent-training modules, with 29% (n = 25/87) preferring therapist contact solely, and 51% (n = 44/87) favouring therapist contact plus access to an online parent support group. Considered together, 80% (79/87) of respondent parents and carers nominated a desire for regular therapist contact to accompany online parenting modules (refer Figure 3.2).

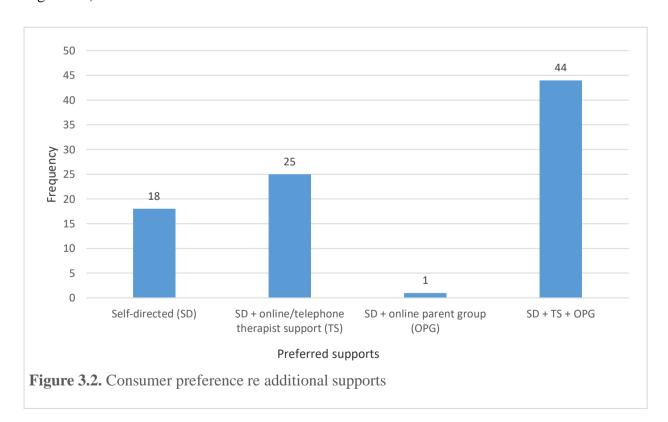
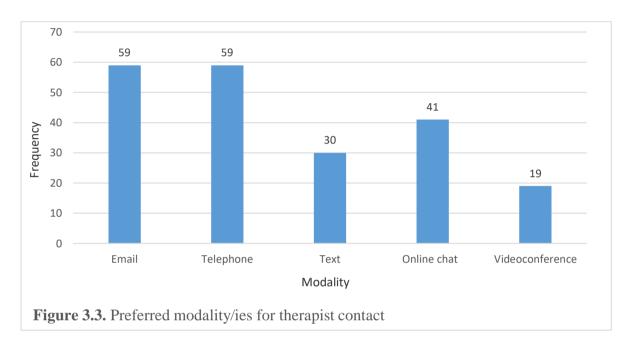
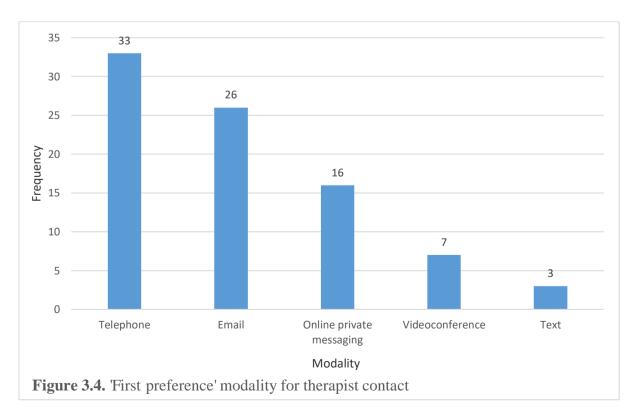


Table 3.2. Respondents' degree of comfort with telecommunication tools

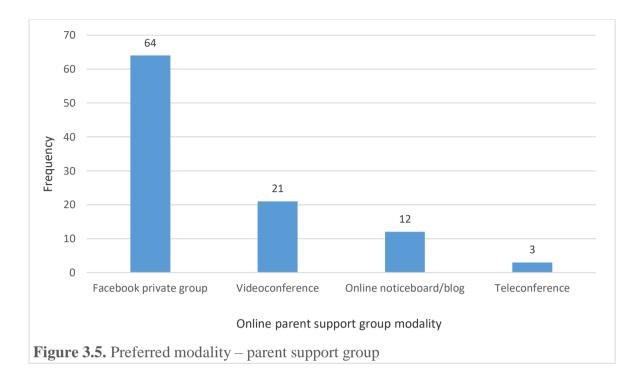
	1 = Do not use	2 = Somewhat uncomfortable	3 = Slightly uncomfortable	4 = Neutral	5 = Slightly comfortable	6 = Somewhat comfortable	7 = Extremely comfortable	Mean	SD
Telecommunication tool	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)		
Facebook Private Group ( $n = 101$ )	26 (26%)	4 (4%)	3 (3%)	7 (7%)	1 (1%)	22 (22%)	38 (37%)	4.69	2.51
Facebook Private Message ( $n = 100$ )	19 (19%)	2 (2%)	1 (1%)	5 (5%)	1 (1%)	26 (26%)	36(46%)	5.29	2.31
Online chat rooms $(n = 94)$	67 (71%)	2 (2%)	4 (4%)	3 (3%)	7 (8%)	7 (8%)	4 (4%)	2.13	1.95
Online noticeboards ( $n = 94$ )	64 (68%)	1 (1%)	5 (5%)	8 (9%)	3 (3%)	7 (8%)	6 (6%)	2.26	2.02
Skype ( $n = 100$ )	33 (33%)	1 (1%)	3 (3%)	12 (12%)	6 (6%)	17 (17%)	28 (28%)	4.20	2.50
Teleconferencing $(n = 93)$	59 (64%)	0 (0%)	4 (4%)	5 (5%)	6 (6%)	8 (9%)	11 (12%)	2.65	2.32
Telephone call $(n = 100)$	6 (6%)	2 (2%)	1 (1%)	6 (6%)	4 (4%)	15 (15%)	66 (66%)	6.09	1.69
Text message $(n = 99)$	2 (2%)	2 (2%)	2 (2%)	3 (3%)	2 (2%)	19 (19%)	69 (70%)	6.37	1.31

When asked to nominate the modality/ies (i.e. multiple response permitted) in which respondents would be happy to receive 'one-on-one' therapist support, telephone consultation and email were equally preferred methods of contact, 68% (n = 59/88) (refer Figure 3.3). When asked to nominate their first preference *only* for therapist support telephone contact 39% (n = 33/85) was favoured over email 31% (n = 26/85), this difference was not significant however (refer Figure 3.4).





Facebook Private Group was the favoured forum for online parent support group contact by 79% (64/81) of respondent parents and carers (refer Figure 3.5).



## **Discussion**

Emerging technologies and ever-expanding, high-speed, low-cost Internet continue to encourage the exploration of telehealth applications as a promising alternative service-delivery model to extend the reach of parenting intervention, without loss of efficacy or satisfaction (Nieuwboer et al., 2013a; Wainer & Ingersoll, 2015). To date, very little research has focused on gaining an insight into the factors that impact on a parents' interest in and willingness to engage in online parenting programmes (Love et al., 2013). With the goal of gaining consumer preference feedback to guide the development of a novel online parenting intervention, the current survey targeted parents and carers of children (aged 0-17 years) with a disability.

In examining current access to, and use of the internet, 100% of survey respondents reported at-home internet access, with 97% of participants using the internet on a regular (at least daily) basis and for a wide variety of purposes - including email, social media, leisure pursuits, shopping and advocacy. Respondents reported varying degrees of comfort with a range of telecommunication services, with particular facility being nominated for telephony, texting and Facebook private messaging. These results suggest the respondent group possessed at least a basic proficiency in using the internet and other popular

telecommunication services – a perhaps not surprising result given the distribution of the survey via weblink.

In an encouraging finding, 89% percent of respondents indicated a willingness to undertake a parenting programme online. Of these, 20% expressed a preference for undertaking this training in a completely self-directed manner with 80% expressing a preference for additional therapist contact to accompany the online programme either with (51%) or without (29%) accompanying online parent support group contact. Telephone and email were (almost) equally popular tools for facilitating therapist contact (68%), while Facebook private group (79%) was the preferred modality for parent-support group contact. For those parents and carers who indicated they would not undertake an online parenting intervention (11%), lack of face-to-face contact, an inability to ask questions or to meet the therapist or other parents were the main concerns expressed.

The present study does have a number of limitations, indicating the need for caution in generalising the results to the broader disability parent-carer population. The survey sample size is small and respondent demographic information was kept to a minimum to encourage greater response, limiting the level of analysis that can be undertaken on the data. Given the online distribution method for the survey, respondent parents and carers were likely to be predisposed to having a degree of telehealth 'fluency', along with a potentially greater openness to participating in online parenting programmes.

#### Conclusion

Little is known about parents' interest in and willingness to engage with telehealth-delivered parenting interventions. This study represents a very early starting point for examining consumer preference in relation to telehealth-based parenting programmes targeting parents and carers of children with a disability. While the need for further, more extensive research with a stronger methodological approach is apparent, the current study does provide some preliminary insights into the acceptability of telehealth parenting programmes for this unique population, along with guidance as to preferred method/s of access and support.

## Chapter 4

## The research protocol of TPOL-D

Living with a child with disability can have substantial and profound effects on all aspects of family life (Reichman et al., 2008). A range of social, emotional, cognitive and adaptive skills deficits are commonly experienced by children with disabilities (Matson, Mahan, & LoVullo, 2009). With estimates of maladaptive behaviours in this population varying from 20% to 64% (Eisenhower, Baker, & Blacher, 2005; Roberts et al., 2003), children with disabilities are also at significantly greater risk of experiencing emotional and behavioural problems then their typically developing peers. For parents and caregivers, higher levels of stress, worry and depression are common (Einfeld et al., 2013; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Herring et al., 2006). Problem behaviours are likely to be persistent over time (Einfeld et al, 2013; Emerson, 2003; Roberts et al, 2003) and may increase in severity (Stuttard et al. 2014). For the child, problem behaviours such as noncompliance, tantrums, aggression, and self-injury can threaten personal health, safety and well-being as well as their inclusion in social, educational and community activities. For families, these challenging behaviours can be difficult to manage, emotionally distressing and disruptive to everyday routines and activities (Cuijpers, 1999; Plant & Sanders, 2007; Stuttard et al., 2014). The resultant heightened family stress may impact on the quality of familial relationships, compromising the support received by the child and further compounding the disability (Roux et al., 2013; Singer, Ethridge & Aldan, 2007). In the absence of effective and appropriate supports the unique challenges faced by families of children with a disability are likely to be exacerbated (Families Special Interest Research Group of IASSID, 2014).

Parent training is a common route for introducing positive and proactive strategies to reduce challenging behaviour, with parenting programmes based on social learning principles (such as the empirically supported Incredible Years Program [IY; Webster-Stratton, 2010], Parent Management Training — Oregon Model [PMTO; Forgatch & Patterson, 2010], Parent—Child Interaction Therapy [PCIT; Fernandez & Eyberg, 2009] and The Triple P - Positive Parenting Program [Triple P; Sanders, 2012]) being widely acknowledged as the 'gold standard' for promoting childhood wellbeing and preventing emotional and behavioural problems (United Nations, 2009; World Health Organisation, 2009). Traditionally, delivered in an in-person environment to individual familes or small groups of parents, parenting interventions have established efficacy in the prevention and treatment of a range of child

social, emotional and behavioural problems including challenging behaviour in children with disabilities (Kable, Taddeo, Strickland, & Coles, 2016; Matson et al., 2009; Skotarczak & Lee, 2015; Tellegen & Sanders, 2013; Whittingham, Sanders, McKinlay, & Boyd, 2014). Despite the established efficacy of these parenting interventions, parent participation rates at a population level remain low (Jones et al., 2013; Prinz & Sanders, 2007). Seeking to address the barriers associated with in-person attendance and delivery of parenting interventions, alternative access methods for implementing parenting interventions are emerging in the research (Breitenstein et al., 2014).

## Exploring the current use of technology in parenting interventions

With its potential to both expand the reach and cut the cost of providing effective, evidence-based interventions, the use of technology is increasingly being explored for the delivery of health and mental health interventions — including parenting interventions (Hall & Bierman, 2015; Jones et al., 2013; Nieuwboer et al., 2013a). Web-based and digital interventions encompass a broad scope of technologies and treatment approaches ranging from static, informational websites that provide basic education or advice requiring minimal user participation, through to comprehensive web-based programs which may be self-directed or include some degree of therapist guidance or support using email, real-time chat, videoconferencing or similar (Barak, Klein, & Proudfoot, 2009). Broader telehealth-based dissemination tools include mobile phones, text messaging, private messages (social media), video and teleconferencing (Hall & Bierman, 2015).

Comparisons of online interventions with conventional face-to-face therapy have not only shown similar outcomes in treatment results (Kairy, Lehoux, Vincent, & Visintin, 2009), but have also indicated that online programmes deliver parenting support in a manner that overcomes many traditional barriers to treatment such as cost, childcare restrictions, perceived social stigma and so on (Enebrink et al., 2012; Tarver, Daley, Lockwood & Sayal, 2014). With engagement to these programmes being readily available to any parent or carer who has Internet access, along with a basic level of online expertise (Dittman et al., 2014; Funderburk, Ware, Altshuler, & Chaffin, 2008), technology-driven delivery platforms offer the very real potential to both expand reach and reduce cost – for both parents and providers (Ingersoll & Berger, 2015; Jones et al., 2013; Macdonell & Prinz, 2016; Wainer & Ingersoll, 2015).

## The research protocol

Despite the great promise of online technologies to deliver parenting interventions in a more accessible manner, research into online parenting programmes for parents of children with a disability remains limited. Given the unique challenges faced by parents of children with a disability, and the significant impacts that may be experienced by the parent, child, family and broader community when there is a failure to link these families to effective and appropriate supports, the development of accessible, empirically-validated, early intervention, parenting programmes is essential to supporting better outcomes for these children, their families and the community. The following describes the protocol adopted in the development of a technology-assisted intervention targeting parents and carers of children with mixed disabilities. The theoretical basis, study hypotheses, methods and planned analyses for this protocol are outlined.

# Step 1 - Assessing the availability of online interventions for parents of children with a disability

A systematic review was undertaken to identify and review evidence for the availability and effectiveness of online inventions to provide training and education to parents and carers of children (aged 0 – 17 years) with a disability (refer Chapter 2). The search strategy yielded 916 sources (see Figure 2.1). Of these, 893 articles were excluded as clearly not meeting inclusion criteria based on a review of the article's title and abstract. The remaining 23 articles were subjected to a full text review, with six articles meeting inclusion criteria. Post the original search process, two additional articles were detected via a Web of Science search update (April 2014), bringing the final article total to eight. Of these, three were RCTs (reported across five articles) and two were case-series studies (reported across three articles). As outlined in Table 2.1 (Chapter 2), all studies located used web-based information pages as a principal component of the intervention, with only one other online communication method being employed (i.e. synchronous videoconferencing).

With a comprehensive search of the literature revealing only a small number of studies (three RCTs and two pre-post studies) specifically focusing on online parenting programmes for parents and carers of children with a disability, the urgent need for further high-quality RCT trials that develop new, or adapt current, parenting programmes for evaluation with this population in an online delivery modality is supported.

## **Step 2 – Identifying the foundation**

Parent training programmes for children with developmental disabilities showing the strongest evidence have typically been adapted from existing parenting programmes (Einfeld et al., 2013). In developing the current intervention, the evidence-based Triple P Program - and more particularly its online iteration of 'Level 4' Triple P, Triple P Online (TPOL; Turner & Sanders, 2011) - as well as the Level 4 disability-specific variant, Stepping Stones Triple P (SSTP; Sanders, Mazzucchelli, & Studman, 2004), were identified as potential interventions for adaptation.

## **Triple P – Positive Parenting Program (Triple P)**

With the aim of treating and preventing severe behavioural, emotional and developmental problems in children and adolescents by enhancing the knowledge, skills and confidence of their parents, Triple P (Triple P; Sanders, 2012) is one of a group of Behavioural Family Interventions (BFIs), derived from social learning, functional analysis and cognitive-behavioural principles (Sanders, Bor, & Morawska, 2007). Offering a multilevel system of parenting intervention (ranging from 'light touch' to intensive, targeted inventions), Triple P adopts a self-regulatory framework for parents. The program has been evaluated extensively in RCT trials, as well as through several meta-analyses, which demonstrated strong effects on child behaviour outcomes and parenting effectiveness (de Graaf, Speetjens, Smit, de Wolff, & Tavecchio, 2008a, 2008b; Nowak & Heinrichs, 2008; Sanders et al., 2014; Thomas & Zimmer-Gembeck, 2007). Level 4 Triple P is an intensive training programme of 8-10 sessions for parents of children with more severe behavioural difficulties. It has several variations, including programmes targeting parents of children up to 12 years of age, teenagers and children with disabilities. While founded on common theory, principles and strategies, each programme variant has some unique content and targets a different population.

## **Triple P Online (TPOL)**

Recently, a web-based version of Level 4 Triple P – Triple P Online (TPOL; Turner & Sanders, 2011) – has been developed, with empirical trials showing promising results (Day, 2016; Love et al., 2016; Sanders et al., 2014; Sanders et al., 2012). Delivered via the Internet, TPOL consists of eight, self-directed modules providing instruction in the use of 17

core positive parenting skills. Topics covered include: (1) What is positive parenting?; (2) Encouraging behavior you like; (3) Teaching new skills; (4) Managing misbehavior; (5) Dealing with disobedience; (6) Preventing problems by planning ahead; (7) Making shopping fun; and (8) Raising confident, capable kids. Completed in sequential format (i.e., module completion opens access to the next module), the interactive programme includes videobased modelling of parenting skills, parent-driven branching to review or gain information, personalised goal setting and probes and exercises to assist parents in checking mastery. Given its promising evidence base and ready online accessibility, TPOL was selected as the foundation programme for TPOL-D.

Figure 4.1a-c shows three screenshots taken directly from the programme. Figure 4.1a displays the Home screen menu, with the unlocked and locked modules depending on current progress. Figure 4.1b displays the downloadable resource selection screen, while Figure 4.1c shows an in-progress screenshot of a user completing a module.

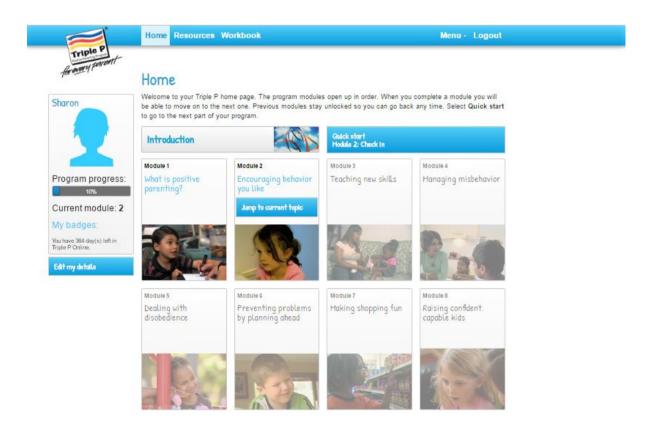


Figure 4.1 Home screen view

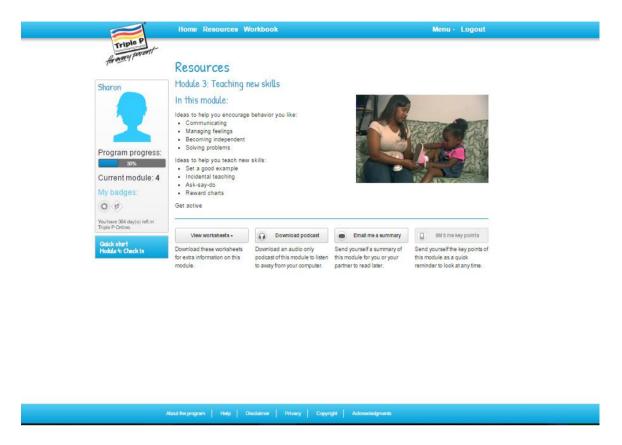


Figure 4.2. Downloadable resources available by module



Figure 4.3. In-progress screen shot of TPOL Module 4

## **Stepping Stones Triple P (SSTP)**

While another variation of Triple P – Stepping Stones Triple P (SSTP; Sanders, Mazzucchelli, & Studman, 2004) – has been specifically developed and trialled for parents of children with a disability, the programme is not available in an online format. Notably, SSTP delivers the same information and module sequencing as that found in Triple P and TPOL, but 'extends' learnings to incorporate unique disability-specific information and strategies. Further, the visual content and imagery in SSTP focuses on children with disabilities, rather than 'typically developing' children thus ensuring that parents of children with a disability will relate to the materials.

As SSTP has previously been evaluated with children with mixed disabilities such as Down syndrome (Roberts et al., 2006), cerebral palsy (Whittingham et al., 2014), autism spectrum disorders (Whittingham, Sofronoff, Sheffield, & Sanders, 2009), and acquired brain injury (Brown et al., 2014), the incorporation of the unique disability-specific content covered in SSTP (but missing from TPOL) was considered essential when creating TPOL-D. To achieve this in an economically-viable manner, two companion, hard-copy resources were provided to all intervention parents (a DVD - SSTP: A survival guide for families with a child who has a disability and a handbook - SSTP: A guide to positive parenting), with the pertinent content from these resources being synchronously programmed for delivery with the relevant weekly TPOL web-based module. Adding an element of flexibility, participants could choose to use one or both resources (which replicated the same content in different formats) depending on their individual learning preferences and family circumstances.

Even with the addition of the Stepping Stones hard copy resources to the Triple P Online (TPOL) modules, the current intervention could not be considered Stepping Stones Online. The visual content and examples used in SSTP aim to maximise parental engagement and uptake by using highly relatable images of children with different disabilities to illustrate strategies and skills (refer Figure 4.2 for series of screenshots taken from the DVD SSTP: A survival guide for families with a child who has a disability).

As an online intervention originally developed for parents and carers of typically developing children, TPOL does not include any images, examples or demonstrations using children with a disability. While parents who participated in TPOL-D were made aware that the online modules had been originally created for parents and carers of typically developing children (and that all imagery would be of typically developing children) a significant concern in developing the current intervention was that parents would be unable and/or

unwilling to extrapolate the strategies demonstrated by 'typically developing' children to the needs of their child with a disability. The unique, but somewhat hybridised, nature of the current intervention, it's content and delivery formats was recognised in the naming of the intervention as TPOL-D.



**Figure 4.4.** Screenshots from DVD SSTP: A survival guide for families with a child who has a disability

## Step 3: Assessing consumer preference re additional telehealth supports

With the success of any parenting programme depending on both the willingness of parents to engage, as well as the feasibility of such engagement (Love et al., 2013) the final stage in developing TPOL-D involved focus group consultation to assess consumer preferences in telehealth-based parenting programs, including any desired additional supports. Using a web-based, questionnaire link (SurveyMonkey), disseminated via relevant support agencies on an Australia-wide basis, 101 responses from eligible parents and carers of children (aged 0 – 17 years) were received between March and July 2014. A \$100 gift card was offered as a small incentive to survey completion, however parents could also choose to respond anonymously. Drawing upon the consumer-preference information received, several novel variations were incorporated into TPOL-D.

## 1. Flexibility of telehealth-facilitated contact

The first of these variations involved the inclusion of an optional, weekly telephone or email session, with a SSTP-accredited facilitator. This contact provided an opportunity for parents to clarify module content, gain assistance in customising strategies and engage in supported problem solving with both family and disability-specific concerns. Sessions were scheduled to occur at the same time each week, with parents strongly encouraged to complete their weekly online module and hard-copy readings prior to facilitator contact. With the exception of two Australian parents temporarily residing overseas (Sweden and USA), consultation times were initially scheduled as a telephone call, however participants were subsequently advised in their Week 1 contact that facilitator support could be accessed via telephone or email. Parents were also offered the opportunity to email prior to their weekly appointment if they did not require facilitator contact in any week. In combination, these variations provided significant flexibility in relation to both the type and amount of facilitator support parents received – with control of these features residing with the parent.

## 2. Social media-based parent support group

A further novel support incorporated into TPOL-D based on survey feedback was a private Facebook 'parent support group'. With the sole purpose of facilitating intra-parent contact, inclusion in the group was optional with interested parents being added by the administrator upon entering Week 1 of the intervention. No additional content in relation to TPOL-D was provided in this group, however reminders in relation to questionnaires being

due were posted. The site was monitored by the facilitator (administrator), and notices posted in relation to relevant community events and activities.

#### 3. Personalised timetables (visual schedulers)

A final support added to TPOL-D was personalised timetables, which were emailed to all participants upon intervention allocation. These simple 'visual schedulers', provided week-by-week guidance as to programme expectations and content deliverables including module completion dates, additional disability-specific DVD/handbook learnings and scheduled appointment times. These were discussed in weekly facilitator sessions to help parents track their progress through the modules and hard-copy content.

## Aims and objectives of study

The primary aim of the study is to evaluate the efficacy of a novel telehealth parenting intervention (TPOL-D) for parents and carers of children with a disability. The objective is to evaluate, using a randomised controlled trial, the efficacy of the TPOL-D intervention for this population. The primary outcomes will be: (1) child behavioural and emotional functioning; and (2) parental skills and self-efficacy. Secondary outcomes will include: (1) intervention adherence; (2) overall satisfaction with TPOL-D; (3) therapist identification and alliance; (4) perceived helpfulness of the individual components of TPOL-D; (5) 'useability' of online modules; and (6) future consumer preference and advocacy issues. It is hypothesised that, relative to the treatment-as-usual (TAU) control group, the intervention group will demonstrate significant improvements on the outcome variables. It is also predicted that any gains made throughout treatment will be maintained at a three-month follow-up.

#### **Design**

The design of the RCT is a mixed design between groups (Intervention and Treatment as usual – TAU) and across time (pre-, post-, and follow up). For the intervention group, assessments of outcome measures will be undertaken through parent questionnaires completed on three occasions (i.e., pre- and post-intervention and three-months post intervention completion). The TAU control group will complete one additional set of questionnaires (i.e., pre- and post- control, post-intervention and three-months post intervention). The study design and processes received ethics approval from the Health and Behavioural Sciences ethics committee at the University of Queensland in accordance with the standards of the National Health and Medical Research Council of Australia.

## **Participants**

#### Inclusion and exclusion criteria

Participants will be English-speaking, consenting parents or carers of a child with a disability aged 2 - 12 years. No limitation will be placed on the nature of the disability; however, a diagnosis is required by a paediatrician, psychiatrist, psychologist, speech pathologist, occupational therapist or neurologist.

#### Sample size

Power analysis indicates that to detect a large effect size for changes in child behaviour, with an alpha of .05 and power set to .8, a sample size of 26 participants per group is required (Cohen, 1992). In keeping with research in relation to attrition rates from parenting programmes, a generous margin of 35 parents per group was set for minimum recruitment, with a total sample size of 70 families.

#### Recruitment

Parents and carers of children (aged 2 - 12 years) with a disability will be recruited through direct email to disability support agencies and community support groups, media releases, established Triple P networks and Triple P/SSTP-associated websites. Additional external advertising is anticipated via University websites, media releases and direct promotion at SSTP seminars and promotional engagements. Only one parent per family will be included in the study. Recruitment and enrolment to the study commenced in mid-2014 and is anticipated to continue through to early 2016, with outcome data being analysed in mid-2016.

Participants will be assessed for eligibility and enrolled in the study by the study coordinator. To reinforce the 'self-help' modality, the study will be explained to parents via emailed information sheets, a dedicated registration website and (if required) clarification emails. No in-person contact will occur at any time.

Written consent will be obtained electronically on the registration website, with parents acknowledging that they are aware of the study requirements, providing consent to take part and acknowledging their understanding that they are free to withdraw from the study at any time.

#### **Randomisation**

The randomisation process will be computer generated (<u>www.randomization.com</u>) in a two-group design (intervention and TAU). Given the nature of the design, no parties will be blinded to group assignment.

## Therapy protocols and delivery

#### **Format**

The intervention will be delivered in an online format (password protected), with supplementary SSTP supports (DVD and handbook) being mailed to all participants prior to commencement. Participants will also be emailed an information sheet including their access details and a personalised timetable for the programme, which will advise them as to how to integrate the use of the additional SSTP resources with their weekly online modules. Parents in the TAU group will receive the same intervention after the delay. In two parent families, both parents will be encouraged to work through TPOL (D) together, however the same parent will undertake the questionnaires at each time point.

## **Therapist**

Telephone consultations will be conducted by a SSTP accredited, registered psychologist and supervision will be conducted by an experienced clinical psychologist.

#### Other treatments

For ethical reasons, treatment as usual will continue for both treatment and control groups, however parents will report on any additional support during the wait-list and intervention phases.

#### **Outcome measures and procedures**

## **Participant characteristics**

Demographic and family background data (including family composition, educational and financial information, biographical information about the child and the child's disability, and the family's use of medical and allied health services) will be collected via parent-report prior to commencement of the intervention. This questionnaire will only be available online and will form part of the registration process.

#### **Outcomes of the parenting programme**

Based on previous Triple P and/or SSTP research, the following questionnaires will be completed. Time points for completion are indicated within each heading. Due to the 'mixed disabilities' nature of the recruitment, two measures of child behaviour, with slightly different focus populations (DBC-P: intellectual disability and CAPES-DD: range of disabilities) will be used to test the hypothesis that there will be a significant decrease in parent-reported child behaviour problems in the intervention group post-completion of TPOL-D when compared with the TAU group.

**Developmental Behaviour Checklist** – **Primary Carer version** (DBC-P; Einfield & Tonge, 2002). All Time Points – Intervention and TAU control. The DBC-P is a 96-item instrument which assesses behavioural and emotional problems in children and adolescents (aged 4-18) with an intellectual disability. It has good psychometric properties (Einfeld & Tonge, 1995) with high inter-rater reliability between parents (ICC = .80), high test-retest reliability (ICC = .83), and excellent internal consistency (Cronbach's  $\alpha$  = .94). The total score on the DBC-P correlates with child psychiatrists' ratings of severity of psychopathology (r = .81).

Child Adjustment and Parent Efficacy Scale – Developmental Disability (CAPES-DD; Emser, Mazzucchelli, Christiansen, & Sanders, 2016). All Time Points – Intervention and TAU control. The CAPES-DD consists of 24 items and assesses behavioural and emotional problems, as well as prosocial behaviour and skills in children aged 2-16 years with a range of disabilities. Psychometric evaluation of the CAPES-DD reveals very good convergent and predictive validity (Emser et al., 2016). Scales have satisfactory to very good internal consistency, specifically, Total problems scale ( $\alpha$  = .90), Self-efficacy scale ( $\alpha$  = .94) and Prosocial behaviour scale ( $\alpha$  = .82), with the Behavioural problems subscale ( $\alpha$  = .89) and Emotional problems subscale (.71) demonstrating between acceptable and good levels of internal consistency.

Parenting and Family Adjustment Scale (PAFAS; Sanders & Morawska, 2010). All Time Points – Intervention and TAU control. The PAFAS is a 30-item measure of family functioning, designed to assess changes in parenting practices and parental adjustment (Sanders, Morawska, Haslam, Filus & Fletcher, 2014). The PAFAS consists of two scales, the Parenting Scale which measures parenting practices and the quality of the parent-child relationship, and the Family Adjustment scale which measures emotional adjustment of

parents, as well as parent and family support experienced in parenting (Sanders et al., 2014). Psychometric research has demonstrated that the PAFAS has good internal consistency, and both construct and predictive validity are satisfactory (Sanders et al., 2014). Specifically, PAFAS Parenting subscales including Parental Consistency, Coercive Parenting, Positive Encouragement and Parent-Child Relationship all demonstrated between acceptable and good levels of internal consistency, with  $\alpha = .70$ ,  $\alpha = .78$ ,  $\alpha = .75$  and  $\alpha = .85$  respectively (Sanders et al., 2014). For the Family Adjustment Scale, the Parental Adjustment, Family Adjustment and Family Relationships subscales all demonstrated good internal consistency, with  $\alpha = .87$ ,  $\alpha = .84$ , and  $\alpha = .85$  respectively (Sanders et al., 2014).

Client Satisfaction Questionnaire (CSQ; Sanders, Markie-Dadds & Turner, 2012). Post completion of intervention – Intervention. The CSQ is a 16-item questionnaire that measures consumer satisfaction with parenting programmes and provides opportunity for feedback. Consisting of 13 items rated on a seven point scale, and three items with openended responses, it is an adaptation of the Therapy Attitude Inventory (Eyberg, 1993).

Working Alliance Inventory – Short Revised (WAI-SR) (Hatcher & Gillaspy, 2006). Post completion of intervention – Intervention. The working relationship or alliance between client and therapist has long been established as a universal agent of change, and is a significant predictor of treatment outcomes (Horvath & Greenberg, 1989). The Working Alliance Inventory-Short Revised (WAI-SR) is a refined 12 item measure of the therapeutic alliance that assesses three key aspects of the therapeutic alliance: (a) agreement on the tasks of therapy, (b) agreement on the goals of therapy and (c) development of an affective bond. Internal consistency scores (coefficient alphas) ranging from .91 to .92 for the total WAI-SR score, .85 to .87 for Goals, .85 to .87 for Tasks, and .85 to .90 for Bond have been reported (Hatcher and Gillaspy, 2006).

Satisfaction with Technology and Utility of Supports Questionnaires. Post completion of intervention – Intervention. Two questionnaires will be developed to measure: a) consumer satisfaction with the functionality of the online modules e.g. accessibility, speed, intuitiveness and so on; and b) consumer perceptions in regard the utility of the individual components of TPOL-D e.g., therapist contact, online modules, SSTP handbook and so on. Both questionnaires will be modelled on similar resources available in the literature in relation to telehealth-delivered interventions.

A number of stand-alone questions will also be incorporated to assess participant's: (a) perceptions in relation to their therapist; and (b) preferred modality of accessing future parenting programmes.

## Protocol adherence and treatment fidelity

One therapist will conduct all telephone sessions, and session checklists will be used to track adherence to the programme protocol. Module completion will be tracked via the 'back end' of the TPOL programme.

#### Completion and withdrawal

Recognising the multiple-resource nature of TPOL-D where skills can be learnt from both the online modules and hard-copy resources, parents and carers in the intervention group will be considered to have completed the programme if they finish (as a minimum) Modules 1 - 4 of the online modules plus pre- and post- intervention assessments. While Module 5 does provide additional learning content, modules 6-8 of TPOL do not. Rather, these modules offer parents the opportunity to plan for and practice their skills in specific situations. As such, completion of Module 4 will ensure the vast majority of required learnings are undertaken, even in the event that parents are not accessing this content from their other resources.

Parents who complete pre-intervention assessment but complete fewer than four modules may have their data included in intention-to-treat analyses. Parents who are discovered to not meet inclusion criteria will be excluded from analyses, as this will be considered a deviation from the protocol. Parents who wish to withdraw will be informed of other treatment options.

#### Planned data analyses

Analyses will be undertaken using the SPSS statistical package, with the usual data screening processes and assumption checking. Analysis of variance (ANOVA) will be undertaken to evaluate outcome over time and between groups. Effect sizes will be calculated for each measure and within each intervention condition, in order to evaluate the level of clinically significant change at post-intervention and three-month follow-up. Scores on measures of child emotional and behavioural outcomes, as well as parenting skills, adjustment and efficacy will be the primary outcome measures, with the remainder of the outcomes forming secondary analyses.

## **Conclusion**

A research protocol is presented for a randomised controlled trial comparing TPOL-D to a TAU control group, for parents and carers of a child (aged 2 - 12 years) with a disability. To the authors' knowledge, TPOL-D is the first telehealth-delivered parenting program to be trialled with parents and carers of children with mixed disabilities.

# Chapter 5

A randomized controlled trial of a telehealth parenting intervention:

A mixed-disability trial

This chapter consists entirely of the following paper.

**Hinton, S.,** Sheffield, S., Sanders, M.R,. & Sofronoff, K. (2017). A randomized controlled trial of a telehealth parenting intervention: A mixed-disability trial. *Research in Developmental Disabilities*. 65, 74-85. https://doi.org/10.1016/j.ridd.2017.04.005

As required by the University of Queensland, the Accepted Author Manuscript of this paper is provided as Chapter 5.

#### **Abstract**

The quality of parenting a child receives has a major impact on development, wellbeing and future life opportunities. This study examined the efficacy of Triple P Online – Disability (TPOL-D) a telehealth intervention for parents of children with a disability. Ninety-eight parents and carers of children aged 2 to 12 years diagnosed with a range of developmental, intellectual and physical disabilities were randomly assigned to either the intervention (51) or treatment-as-usual (47) control group. At post-intervention parents receiving the TPOL-D intervention demonstrated significant improvements in parenting self-efficacy, parenting style, parental adjustment and family relationships. At 3-month follow up intervention gains were maintained and/or enhanced. A significant decrease in parent-reported child behavioral and emotional problems was also detected at this time. The results indicate that TPOL-D is a promising telehealth intervention for a mixed-disability group. Limitations of the study and future research directions are discussed.

Keywords: Parenting, Disability, Telehealth, Online parent training, Triple P Online-Disability

#### 1. Introduction

Problem behavior is one of the most enduring and pervasive challenges experienced by children with disability, their families, professionals, and the community at large. For families, problem behaviors such as tantrums, aggression and self-injury can be difficult to manage, emotionally distressing and disruptive to everyday routines, leading to increased stress, worry and depression (Einfeld, Tonge, & Clarke, 2013). For the children themselves, such behaviors can threaten personal health, safety and well-being as well as their inclusion in social, educational and community activities (Stuttard et al., 2014). With the prevalence of problem behaviors in children with intellectual or developmental disabilities being significantly higher than in typically developing children (Einfeld & Tonge, 1996), the unique combination of difficulties experienced can present a formidable set of challenges for parents and carers.

There is a growing consensus that the quality of parenting a child receives has a substantial impact on development, emotional functioning, language, social skills and future life opportunities (Stack, Serbin, Enns, Ruttle, & Barrieau, 2010). More specifically, positive parenting programs based on social learning and cognitive-behavioral principles have been found to be particularly effective in reducing emotional and behavioral problems in children and adolescents. Those that also incorporate 'live' (i.e., in-session) coaching of skills have been found to result in even greater gains in parenting skills and larger reductions in child problem behaviors (Kaminski, Valle, Filene, & Boyle, 2008; Wade, Oberjohn, Conaway, Osinka & Bangert, 2011). While reviews of parenting interventions specifically for children with developmental delay and/or disability are more limited, these have shown similar positive results (Antonini et al., 2014; Stuttard et al., 2014; Tellegen & Sanders, 2013; Whittingham, Sanders, McKinlay, & Boyd, 2014).

Given the efficacy of parenting interventions in improving child outcomes in both typically-developing children and children with a disability, it is unsurprising that programs that enhance parents' self-sufficiency in managing their children's behavior and environment have become a common route for early intervention. Despite both the availability and established effectiveness of evidence-based parenting programs, parent participation remains low (Sanders, Baker, & Turner, 2012). For parents, attendance in the traditional face-to-face modality has many well-documented challenges both logistical and personal, such as availability of alternative carers, cost, cultural barriers, perceived social stigma and so on

(Breitenstein, Gross, & Christophersen, 2014; Enebrink, Högström, Forster, & Ghaderi, 2012). For service providers, common barriers to delivery include availability of funding; third party funding approval processes; availability of appropriately trained staff and geographical coverage issues (Love, Sanders, Metzler, Prinz, & Kast, 2013). With regular attendance at face-to-face parenting programs undoubtedly presenting a challenge for any parent, for parents of children with disabilities such barriers are likely to be further exacerbated by the need for specialized and/or additional resources associated with caring for their children.

With the clear need for more accessible treatment options, online parenting interventions offer the very real potential of helping to alleviate the burden of caring by providing 'anytime, anywhere' assistance to a parent or carer who has Internet access, predicated upon a basic level of Internet knowledge and expertise (Dittman, Farruggia, Palmer, Sanders, & Keown, 2014). While the empirical evidence remains limited, comparisons of online and (more broadly) telehealth parenting interventions with conventional face-to-face therapy have not only shown comparable outcomes in treatment results but have also indicated that these programs deliver parenting support in a manner that overcomes many of the traditional barriers to support, while maintaining high levels of client satisfaction (Enebrink et al., 2012; Sanders et al., 2012). Despite these encouraging findings, there remain few empirically validated parenting programs available in an online or telehealth delivery modality, and even fewer programs that specifically target, and/or include, adaptations to meet the specific needs of parents and caregivers of children with a disability (Antonini et al., 2014; Kable, Coles, Strickland & Taddeo, 2012; Wade et al., 2014).

### 1.1. Research Questions

The primary aim of the current study was to investigate the efficacy of a telehealth-based parenting intervention for parents of children with a disability. A 'treatment as usual' control group was chosen as the comparator to allow for evaluation of the intervention against current practice. Based on outcomes from similar in-person and telehealth-based parenting programs (Antonini et al., 2014; Brown, Whittingham, Boyd, & McKinlay, 2014; Enebrink et al., 2012; Roux, Sofronoff & Sanders, 2013; Sanders, Dittman, Farruggia, & Keown, 2014; Sanders et al., 2012), the central hypotheses was that, compared to parents in a treatment-as-usual control condition, parents who completed TPOL-D would report a decrease in child behavior problems as well as significant improvements in parenting skills and self-efficacy. It was also hypothesized that intervention gains would be maintained at 3-

month follow-up. Lastly, parent satisfaction with TPOL-D was also assessed using the Client Satisfaction Questionnaire (*CSQ*; Sanders, Markie-Dadds, & Turner, 2001)

#### 2. Method

### 2.1 Study design

The study was a randomized, controlled trial following a 2 group (group: TPOL-D vs treatment-as-usual [TAU] control) x 3 time (time: pre-intervention [T1], post-intervention nine-weeks after initial login [T2], three-month follow-up [T3]) repeated measures design. Randomization was achieved using an online computer program (www.randomization.com). Pre-intervention measures (T1) were completed by both the intervention and TAU control group. The intervention group only then received the TPOL-D program. Post-completion of TPOL-D, both the intervention and TAU control completed T2 measures. Following completion of the post-treatment measures, the TAU control group also received TPOL-D. The TAU control received TPOL-D before follow-up data collection for ethical reasons. Post-intervention follow-up with the intervention group only was completed 3 months after TPOL-D completion (T3). Follow-up consisted of assessing treatment maintenance. While undertaking the study, all participants were asked not to participate in another parenting program, however, treatment-as-usual continued for both the treatment and the TAU control for ethical reasons. Figure 1 depicts the flow of study participants in a Consort Diagram.

# Insert Figure 1 about here.

## 2.2 Participants

Power analysis indicated that to detect a large effect size of .8, with alpha set to .05 and power set to .80, a sample size of 26 participants per group would be required (Jacob Cohen, 1992). A large effect size was anticipated, based on a meta-analysis of Level 4 Triple P outcome research undertaken by De Graaf, Speetjens, Smit, De Wolff & Tavecchio (2008a). Previous research has demonstrated a wide variance in relation to completion rates for online interventions (Baumeister, Reichler, Munzinger & Lin, 2014; Bennett-Levy, 2010; van Ballegooijen et al., 2014) with, more specifically, a systematic review of digital delivery methods of parenting training interventions finding a completion rate of between 41.7% and 99.2% (Breitenstein et al, 2014). While a generous margin of 35 parents per group was set for minimum recruitment, 98 parents who applied and were eligible to participate at the close-off date of the final cycle were accepted – as numbers fell far short of the 64 per group required for a medium effect size (Cohen, 1992). In total, 113 eligible parents registered for participation in TPOL-D, with 15 (13%) declining to participate further post eligibility

assessment. It was not possible to blind participants to knowledge of group allocation post-assignment. No limitation was placed on the nature of the child's disability; however, eligibility requirements required diagnosis from a Neurologist, Psychiatrist, Psychologist, Speech Pathologist or Occupational Therapist, as well as child age between 2 and 12 years (at point of recruitment). Only one parent per family was accepted into the research, although parents were encouraged to work through the program with a partner or friend, if desired.

In all, 78% of participants were seeking treatment to address the behavior of a male child. Behavioral problems were based on parent identification and were not required to meet a threshold for inclusion in the study. At pre-intervention, no significant differences between the groups was detected using Chi-square analysis and ANOVA, as appropriate. The disability mix was similar between the two groups, with ASD being the most prevalent diagnosis. Participant demographics are presented in Table 1.

#### Insert Table 1 about here

#### 2.3 Procedure

Ethical approval for the project was obtained from the University of Queensland in accordance with National Health and Medical Research Council of Australia standards; ethics approval number 2012001065. Australia-wide recruitment was conducted over a 12-month period via community outreach in mass media, disability support associations, support groups and schools with a Special Education Unit (Queensland only). Post email inquiry, parents were forwarded a detailed information flyer outlining the program structure, content, timings and technology requirements - along with a link that allowed them to review the online program interface. Parents were informed that the program was being offered with staggered start dates throughout the year and that each 'cycle' would have two possible start dates for which they would need to be available.

One week prior to commencement of each cycle of the intervention, interested parents were invited to complete online registration and informed consent, as well as their T1 questionnaires. Post-completion, parents were emailed their TPOL-D commencement date, with the intervention group also receiving their individual log-in details, personalized timetable and supplementary disability-specific resources (via registered mail). Participants allocated to the TAU control group were also emailed information in relation to their (later) program start date and T2 questionnaire timings. To guarantee consistency in the intervention approach, the first author (Masters qualified, SSTP-accredited psychologist) was the remote facilitator for all intervention participants. T2 data was completed by both the intervention

and TAU control immediately following program completion with T3 data (intervention only) being completed three months later.

#### 2.4 Intervention

Triple P Online-Disability (TPOL-D) is a new, telehealth variant of the Triple P-Positive Parenting Program (Triple P; Sanders, 2008). Targeting parents of children (aged 2-12 years) with mixed disabilities, TPOL-D combines elements of the evidence-based Triple P Online (TPOL; Turner & Sanders, 2011) and Stepping Stones Triple P (SSTP: Sanders, Mazzucchelli, & Studman, 2009) programs, with several unique variations.

With the aim of treating and preventing severe behavioral, emotional and developmental problems in children and adolescents by enhancing the knowledge, skills and confidence of their parents, Triple P is one of a group of Behavioral Family Interventions (BFIs), derived from social learning, functional analysis and cognitive-behavioral principles (Sanders, Bor, & Morawska, 2007). Offering a multi-level system of parenting intervention (ranging from 'light touch' to intensive, targeted inventions), Triple P adopts a self-regulatory framework for parents. The program has been evaluated extensively in RCT trials, as well as through several meta-analyses which demonstrated strong effects on child behavior outcomes and parenting effectiveness (de Graaf, Speetjens, Smit, de Wolff, & Tavecchio, 2008a, 2008b; Nowak & Heinrichs, 2008; Sanders et al., 2014; Thomas & Zimmer-Gembeck, 2007). Level 4 Triple P is an intensive training program of 8 – 10 sessions for parents of children with more severe behavioral difficulties. It has several variations, including programs targeting parents of children up to 12 years of age, teenagers and children with disabilities. While founded on common theory, principles and strategies, each program variant has some unique content and targets a different population.

Recently, a web-based version of Level 4 Triple P – Triple P Online (TPOL; Turner & Sanders, 2011) – has been developed, with empirical trials showing promising results (Day, 2016; Love et al., 2016; Sanders et al., 2014; Sanders et al., 2012). Delivered via the internet, TPOL consists of eight, self-directed modules providing instruction in the use of 17 core positive parenting skills. Topics covered include: (1) What is positive parenting?; (2) Encouraging behavior you like; (3) Teaching new skills; (4) Managing misbehavior; (5) Dealing with disobedience; (6) Preventing problems by planning ahead; (7) Making shopping fun; and (8) Raising confident, capable kids. Completed in sequential format (i.e., module completion opens access to the next module), the interactive program includes video-based

modelling of parenting skills, parent-driven branching to review or gain information, personalised goal setting and probes and exercises to assist parents in checking mastery.

Given its promising evidence base and ready online accessibility, TPOL was adapted as the foundation program for TPOL-D. While another variation of Triple P – Stepping Stones Triple P (SSTP; Sanders, Mazzucchelli, & Studman, 2009) – has been specifically developed and trialled for parents of children with a disability, the program is not available in an online format. Notably, SSTP delivers the same information and module sequencing as that found in Triple P and TPOL, but 'extends' learnings to incorporate unique disability-specific information and strategies. Further, the visual content and imagery in SSTP focuses on children with disabilities, rather than 'typically developing' children.

As SSTP has previously been evaluated with children with mixed disabilities such as Down syndrome (Roberts, Mazzucchelli, Studman, & Sanders, 2006), cerebral palsy (Whittingham et al., 2014), autism spectrum disorders (Whittingham, Sofronoff, Sheffield, & Sanders, 2009); and acquired brain injury (Brown et al., 2014), the incorporation of the unique disability-specific content covered in SSTP (but missing from TPOL) was considered essential when creating TPOL-D. To achieve this in an economically-viable manner, two companion, hard-copy resources were provided to all intervention parents (a DVD - SSTP: A survival guide for families with a child who has a disability and an handbook - SSTP: A guide to positive parenting), with the pertinent content from these resources being synchronously programed for delivery with the relevant weekly TPOL web-based module. Adding an element of flexibility, participants could choose to use one or both resources (which replicated the same content in different formats) depending on their individual learning preferences and family circumstances.

Even with the addition of the Stepping Stones hard copy resources to the Triple P Online (TPOL) modules, the current intervention could not be considered Stepping Stones Online. The visual content and examples used in SSTP aim to maximize parental engagement and uptake by using highly relatable images of children with different disabilities to illustrate strategies and skills. As an online intervention originally developed for parents and carers of typically developing children, TPOL does not include any images, examples or demonstrations using children with a disability. While parents who participated in TPOL-D were made aware that the online modules had been originally created for parents and carers of typically developing children (and that all imagery would be of typically developing children) a significant concern in developing the current intervention was that parents would

be unable and/or unwilling to extrapolate the strategies demonstrated by 'typically developing' children to the needs of their child with a disability. The unique, but somewhat hybridized, nature of the current intervention, it's content and delivery formats was recognised in the naming of the intervention as TPOL-D.

With the success of any parenting program depending on both the willingness of parents to engage, as well as the feasibility of such engagement (Love, Sanders, Metzler, Prinz, & Kast, 2013), the final stage in developing TPOL-D involved focus group consultation to assess consumer preferences in regard telehealth-based parenting programs, including any desired additional supports. Utilising a web-based, questionnaire link (SurveyMonkey), disseminated via relevant support agencies on an Australia-wide basis, 101 responses from eligible parents and carers of children (aged 0-17 years) were received between March and July 2014. A \$100 gift card was offered as a small incentive to survey completion, however parents could also choose to respond anonymously. Drawing upon the consumer-preference information received, several novel variations were incorporated into TPOL-D.

The first of these variations involved the inclusion of an optional, weekly telephone or email session, with a SSTP-accredited facilitator. This contact provided an opportunity for parents to clarify module content, gain assistance in customising strategies and engage in supported problem solving in regard both family and disability-specific concerns. Sessions were scheduled to occur at the same time each week, with parents strongly encouraged to complete their weekly online module and hard-copy readings prior to facilitator contact. With the exception of two Australian parents temporarily residing overseas (Sweden and USA), consultation times were initially scheduled as a telephone call, however participants were subsequently advised in their Week 1 contact that facilitator support could be accessed via telephone or email. Parents were also offered the opportunity to email prior to their weekly appointment if they did not require facilitator contact in any week. In combination, these variations provided significant flexibility in relation to both the type and amount of facilitator support parents received – with control of these features residing with the parent.

A further, novel support incorporated into TPOL-D based on focus group feedback was a private Facebook 'parent support group'. With the sole purpose of facilitating intraparent contact, inclusion in the group was optional with interested parents being added by the administrator upon entering Week 1 of the intervention. No additional content in relation to TPOL-D was provided in this group, however reminders in relation to questionnaires being

due were posted. The site was monitored by the facilitator (administrator), and notices posted in relation to relevant community events and activities.

A final support added to TPOL-D was that of personalized timetables, which were emailed to all participants upon intervention allocation. These simple 'visual schedulers', provided week-by-week guidance as to program expectations and content deliverables including module completion dates, additional disability-specific DVD/handbook learnings and scheduled appointment times. These were discussed in weekly facilitator sessions to help parents track their progress through the modules and hard-copy content.

# 2.5 Intervention engagement

On average, parents in the TPOL-D group completed seven modules (SD = 2.16; range 0 to 8). Two parents (4%) did not actively engage with the online intervention, defined as either not logging in at all, or logging in briefly but not completing the first module. Parents further participated in an average of six weekly telephone or email consultations with their remote facilitator, with 80% of these being completed by telephone and 20% by email. Twenty-six parents used a mixture of telephone and email consultations, with two parents using email contact only.

#### 2.6 Outcome measures

Parents in both groups completed online questionnaires both before and after the intervention had taken place. The intervention group completed a further questionnaire three months after completion of the program.

2.6.1 Developmental Behaviour Checklist – Primary Carer version (DBC-P; Einfield & Tonge, 2002).

Completed by a parent or carer, the DBC-P assesses behavioral and emotional problems in children and adolescents (aged 4-18) with an intellectual disability. The 96 items are answered by the primary carer on a 3-point scale (0 = not true as far as you know, 1 = somewhat true, 2 = very true or often true). A score of 46 or more is indicative of clinically significant levels of behavioral and emotional problems. Individual sub-scale scores, and scores on individual items, are useful for assessing the severity of individual problems. The DBC-P has five sub-scales as well as a Total Behaviour Problem Score (TBPS), created from the sum of the individual scores. In this study, internal consistency at pre-intervention for the TBPS was excellent ( $\alpha$  = .96), with individual subscales: Disruptive/Antisocial ( $\alpha$  = .92), Self-Absorbed ( $\alpha$  = .92), Communication Disturbance ( $\alpha$  = .74), Social-Relating ( $\alpha$  = .73) and Anxiety ( $\alpha$  = .72). A parallel version of the DBC-P, the DBC-P-U4, was employed with

caregivers of children under 4 (n = 5), however the results for this measure were omitted from analysis due to insufficient sample size. All other outcome data from these parents was included in analysis.

2.6.2 Child Adjustment and Parent Efficacy Scale – Developmental Disability (CAPES-DD; Emser, Mazzucchelli, Christiansen, & Sanders, 2016).

Completed by any caregiver of the child, the CAPES-DD consists of 24 items and assesses behavioral and emotional problems, as well as prosocial behavior and skills in children aged 2-16 years with a range of disabilities. All 24 items are rated by caregivers based on how true the statement is of their child over the past 4 weeks (0 = not at all, 1 = alittle, 2 = quite a lot, 3 = very much). The Total Problems scale score is obtained by summing the 'how true' ratings of the 10 item Behavioural Problems subscale plus 3 item Emotional Problems subscale plus 3 individual items included on the basis of their clinical relevance - hurts themselves, upset when separated, fusses or refuses to eat. The Prosocial Behaviour scale score is obtained by summing the 'how true' rating of 8 items describing prosocial behaviors. The Self-Efficacy scale score is obtained by summing caregivers' confidence ratings for the behavioral or emotional problems (1 = Certain I can't manage it, to 10 = Certain I can manage it). There are no parent confidence ratings for the Prosocial Behavior scale. As the Prosocial Behavior scale does not report on a key outcome of the current research it was omitted from analysis. Internal consistencies indicated moderate to good values for the Total Problems scale score ( $\alpha = .80$ ) and Self-Efficacy scale ( $\alpha = .89$ ). At a subscale level, Behavioural Problems also reported good internal consistency ( $\alpha = .88$ ), while internal consistency for the Emotional Problems subscale was poor ( $\alpha = .60$ ) (likely a reflection that this subscale has only three items).

2.6.3 The Parenting and Family Adjustment Scales (PAFAS; Sanders & Morawska, 2010).

The PAFAS is a 30-item inventory, consisting of two scales assessing parenting practices – (Parenting scale) and family adjustment (Family Adjustment scale). The 18-item Parenting Scale has four subscales: Parental Consistency, Coercive Parenting, Positive Encouragement, and Parent-Child Relationship. The 12-item Family Adjustment scale has three subscales: Parental Adjustment, Family Relationships, and Parental Teamwork. Each item is rated by the caregiver on a 4-point Likert-type scale and answers are summed for each individual subscale with higher scores indicating higher dysfunction. As the Family Adjustment scale does not report on a key outcome of the current research it was omitted from analysis. In this study, internal consistencies for the Parenting Scale ( $\alpha = .83$ ) was good,

with individual subscales recording: Consistency ( $\alpha = .67$ ), Coercive ( $\alpha = .73$ ), Positive Encouragement ( $\alpha = .78$ ) and Parent-Child Relationship ( $\alpha = .84$ ).

2.6.4 The Client Satisfaction Questionnaire (CSQ; Sanders, Markie-Dadds, & Turner, 2001).

Client satisfaction was assessed using the Client Satisfaction Questionnaire at post-intervention for the intervention group only. The 13-item measure evaluated satisfaction on a range of indicators such as the quality of the service, the extent to which the program met the needs of the family, and whether parents feel the program has equipped them to deal more effectively with problems that arise. Items are rated on a scale of 1 to 7, and a total score ranging between 13 and 91 is obtained by summing the items, with higher scores indicating greater satisfaction. The scale has high internal consistency ( $\alpha = .96$ ) (Sanders, Markie-Dadds, Tully, & Bor, 2000).

#### 3. Results

# 3.1 Preliminary analyses

To check for adequate randomization, preliminary analyses using chi square (categorical variables) and analysis of variance (continuous variables) was conducted to confirm the equivalence of the intervention and TAU control at pre-test on all demographic variables. No significant pre-treatment differences were detected. ANOVA was also undertaken on all outcome variables (means are presented in Table 2). No significant differences were detected between conditions on any variable, indicating that randomization resulted in comparable groups on both sociodemographic measures and the intensity of presenting problems. Similarly, no significant differences in retention rates between conditions from T1 to T2 p = 1.00 (2-sided Fisher's Exact Test) were observed. Given the very small percentage of missing data (0.12%) across all time points (0.05% at T1; 0.16% at T2; and 0.23% at T3), mean substitution of the sample mean was used where data was missing. While the PAFAS and CAPES-DD do not have clinical cut-offs available, the DBC-P reports that a score of 46 or more is indicative of clinically significant levels of behavioral and emotional problems. Both the intervention and TAU control groups reported levels of child behavioral and emotional problems in the clinically significant range at T1. Based on Cohen's (1969) benchmarks, partial eta squared ( $\eta_p^2$ ) was used to demonstrate the effect size, with .0099, .0588 and .1379 representing a small, medium and large effect, respectively (Richardson, 2011).

### 3.2 Statistical analysis approach

A series of ANOVAs were conducted using SPSS (Version 24) to examine differences between the intervention and TAU control groups from T1 to T2. ANOVAs were conducted on the total scores and subscales. A Scheffe adjustment was used to account for the number of analyses conducted. A further series of ANOVAs explored treatment maintenance for the intervention group only. Analyses compared pre-intervention scores (T1) to follow up scores (T3), 3-months post-completion of intervention (i.e. approx. 5 months post commencement of program).

#### 3.3 Pre- to post-intervention treatment effects

Table 2 contains descriptive statistics for both conditions at pre- and post-intervention as well as Time x Group F values and effect sizes.

#### Insert Table 2 about here

# 3.3.1 Parent-reported child behavior

Due to the 'mixed disabilities' nature of the recruitment, two measures of child behavior, with slightly different focus populations (DBC-P: intellectual disability and CAPES-DD: range of disabilities), were used to test the hypothesis that there would be a significant decrease in parent-reported child behavior problems in the intervention group post-completion of TPOL-D when compared with the TAU group. The ANOVA examining differences in overall parent-reported child behavior showed no significant Time x Group interaction, F(2,75) = 2.69, p = ns, and no significant main effect for Time, F(2,75) = 2.63, p = ns, or Group, F(2,75) = .270, p = ns was detected. The results do not provide support for a parent-reported decrease in problematic child behavior post completion of TPOL-D.

#### 3.3.2 Parental self-efficacy

The ANOVA for parental self-efficacy showed a significant Time x Group interaction, F(1,87) = 13.33, p < .001,  $\eta_p^2 = .13$ , as well as a significant main effect for Time, F(1,87) = 14.96, p < .001,  $\eta_p^2 = .015$ , and Group, F(1,87) = 6.49, p < .05,  $\eta_p^2 = .07$ . Results indicate that, in comparison with the TAU group, parents who completed TPOL-D reported significantly increased confidence in managing their child's emotional and behavioral problems.

### 3.3.3 Parenting style

The ANOVA exploring dysfunctional parenting style revealed a Time x Group interaction F(4,84) = 5.93, p < .001,  $\eta_p^2 = .22$ , and a significant main effect for Time, F(4,84)= 3.14, p < .05,  $\eta_p^2 = .13$ , but no significant main effect for Group, F(4.84) = 1.40, p = ns. The interaction revealed that parents who completed TPOL-D reported significant improvements in their parenting practices (such as greater use of descriptive praise, logical consequences and similar strategies) when compared with the TAU group. At a subscale level, the PAFAS Consistency subscale detected a Time x Group interaction, F(1,87) = 8.36, p < .005,  $\eta_p^2 = .09$ , as well as a main effect for Time, F(1.87) = 4.46, p < .05,  $\eta_p^2 = .05$ , but not for Group, F(1.87) = 1.95, p = ns. The Coercive subscale showed a Time x Group interaction, F(1.87) = 12.39, p < .001,  $\eta_p^2 = .13$ , as well as a main effect for Time, F(1.87) =9.39, p < .005,  $\eta_p^2 = .09$ , but not for Group F(1.87) = 1.31, p = ns. The Positive Encouragement subscale showed a Time x Group interaction, F(1.87) = 15.33, p < .001,  $\eta_p^2 =$ .15, but did not show a main effect for Time, F(1.87) = 9.39, p = ns, or Group, F(1.87) =.833, p = ns. Similarly, the Parent-Child Relationship subscale showed a Time x Group interaction, F(1.87) = 5.62, p < .05,  $\eta_0^2 = .06$ , but did not show a main effect for Time, F(1.87) = 3.03, p = ns, or Group, F(1.87) = .51, p = ns. Results indicate that when compared to the TAU control, parents who completed TPOL-D showed a significant improvement in parenting practices including greater consistency, decreased use of coercive behaviors, increased use of positive encouragers and an improved parent-child relationship.

#### 3.4 Maintenance of treatment effects

A series of ANOVAs were used to assess whether the TPOL-D group maintained the gains made, at follow-up (i.e. 3-months later), by comparing T1 to T3 scores. Of the 51 participants in the intervention group, 38 parents completed the T3 follow-up questionnaires. Intention to Treat (ITT) analyses were also conducted on the data by using the highly conservative method of carrying forward the scores of the missing eight parents from their pre-intervention questionnaires into their follow-up data (n = 46). The ITT analyses did not show any significant differences to that of the 'completer parents' analyses and there were no changes to the substantive interpretations. As such, and for ease of interpretation, the full data set for completer parents (n = 38) was reported (refer Table 3). The means and standard deviations are summarised in Table 3.

#### 3.4.1 Child behavior

Although non-significant at T2, as one of the key outcome measures it was considered appropriate to re-examine child behavior in the within-subjects analysis, particularly as the mean for the DBC-P total score at T3 was observed to be below the clinical cut-off for child behavioral and emotional problems. The ANOVA examining global parent-reported child behavior showed a significant effect for Time, F(2,33) = 14.41, p < .001,  $\eta_p^2 =$ .47. Examination at an individual scale level showed a significant effect for both the DBC Total Behaviour Problem scale, F(1, 34) = 29.47, p < .001,  $\eta_p^2 = .46$ , and the CAPES-DD Total Problems scale, F(1,37) = 16.95, p < .001,  $\eta_p^2 = .31$ . Further examination at a subscale level for both measures showed all subscales also to be significant for Time – DBC-P; Disruptive/Antisocial F(1,34) = 3124, p < .001,  $\eta_p^2 = .48$ , Self-Absorbed F(1,34) = 17.68, p < .001.001,  $\eta_p^2 = .34$ , Communication Disturbance F(1,34) = 26.91, p < .001,  $\eta_p^2 = .44$ , Anxiety  $F(1,34) = 9.68, p < .005, \eta_p^2 = .22$ , Social Relating  $F(1,34) = 9.19, p < .005, \eta_p^2 = .21$ , CAPES-DD; Emotional F(1,37) = 9.16, p < .005,  $\eta_p^2 = .21$ , Behavioural F(1,37) = 19.12, p < .005.001,  $\eta_p^2 = .34$ . The results indicate that parent-reported child behavioral and emotional problems significantly decreased from T1 to T3, perhaps indicating the presence of a 'sleeper effect' in regard to this outcome.

# 3.4.2 Parental self-efficacy

The ANOVA for parent self-efficacy showed a significant effect for Time, F(1,37) = 36.60, p < .001,  $\eta_p^2 = .49$ , indicating that parents experienced a significant improvement in confidence in relation to managing the problem behaviors of their child from T1 to T3.

## 3.4.3 Parenting style

The ANOVA for parenting style showed a significant effect for Time, F(4,34) = 8.94, p < .001,  $\eta_p^2 = .5$ . Examination at an individual level revealed significant outcomes on all subscales; Consistency, F(1,37) = 21.55, p < .001,  $\eta_p^2 = .37$ , Positive Encouragement, F(1,37) = 22.35, p < .001,  $\eta_p^2 = .39$ , Parent-Child Relationship F(1,37) = 9.46, p < .005,  $\eta_p^2 = .20$ , Coercive F(1,37) = 22.43, p < .001,  $\eta_p^2 = 38$ . The results indicate that parents experienced a significant decrease in dysfunctional parenting practices from T1 to T3.

### 3.5 Parent satisfaction with TPOL-D

As measured by the CSQ, Parents in the intervention group reported high levels of satisfaction with TPOL-D. Ninety-six percent of participants rated the quality of service they received as 'good' with 98% of parents stating that they were at least 'satisfied' with the program. Similarly, 96% of parents also felt that the TPOL-D program helped them deal more effectively with their child's problem behaviors.

#### 4. Discussion

Online technologies offer the very real potential for parents of children with a disability to overcome many of the common barriers to training and support (Nieuwboer et al., 2013). Unfortunately, empirically-validated, telehealth-based parent training programs for parents of children with a disability are scarce – with programs catering to disability diverse syndromes being even rarer (if available at all). To the authors' knowledge, TPOL-D is the first completely telehealth-facilitated parenting program to be trialled with parents and carers of children with a diverse range of intellectual, developmental and physical disabilities. The aim of the current research was to assess the efficacy of a telehealth-based parenting intervention for parents of children with mixed disabilities using parent-reported child behavioral and emotional problems, parenting skills and parental self-efficacy as key outcome measures.

### 4.1 Intervention effects

Consistent with the primary hypothesis and previous research in the area (Roux et al., 2013; Sanders et al., 2012), immediately post TPOL-D completion parents in the intervention group reported significant improvements in their parenting style and feelings of self-efficacy when compared with the TAU group. TPOL-D parents indicated that they had greater confidence in managing their child's problem behaviors, were more consistent in their parenting practices, used fewer coercive behaviors, more positive encouragers and enjoyed an improved parent-child relationship. Examination of treatment gains at 3-month follow-up (i.e. 5-months post commencement of TPOL-D) revealed that these improvements were either maintained or enhanced across time – lending support to the potential durability of these changes.

While parents in both the intervention and TAU control group reported clinically-significant levels of child behavior and emotional problems at T1, in contrast to previous research findings (Day, 2016; Sanders et al., 2014; Sanders et al., 2012; Whittingham et al., 2009), the hypothesis that parents in the TPOL-D would report a significant decrease in child

problem behaviors from pre- to post-intervention in comparison with the TAU group was not supported. Parents in the TPOL-D group did however report decreased problem behaviors across time, falling below clinical cut-off at T3. While within-subjects analysis also detected a significant decrease in parent-report child behavior from T1 to T3, the lack of a significant result in the controlled analysis (T1-T2) requires caution to be exercised in interpreting the result. Notably, parents in the TPOL-D group did not report undertaking any other parenting program or parent training in the 3-month follow up period, so an intuitive explanation may be that, post-completion of TPOL-D, parents experienced a degree of uncertainty in relation to maintaining the gains they had made without the assistance of their weekly therapist support. On this basis, these parents took somewhat longer to establish, employ and gain mastery of the behavior management skills learned during the program. An alternative hypothesis (based on comments made to the facilitator in support sessions) is that parents may have entered the program with a specific desire to improve their own parenting practices and skills and enhance the relationship with their child, rather than to change their child's behaviors. The learning of such parenting skills may have, therefore, been the initial focus of their observations. While this approach would undoubtedly indicate a considerable amount of insight on the part of the parents, it remains an area that would benefit from exploration in future research. Regardless, further research is necessary to determine whether the result is the product of a true sleeper effect.

## 4.2 Consumer engagement and satisfaction

On average parents in the intervention completed seven online modules and participated in an average of six weekly telephone or email consultations, with 52% of parents adopting a mixture of telephone and email consultations – achieving a high level of 'treatment dosage'. It is likely that the flexibility in access to content, resources and facilitator support contributed to the generally successful outcomes achieved in this mixed disability group, with parents effectively being able to decide: a) when and where they accessed the TPOL modules; b) when and if they used the additional SSTP hardcopy resources; c) the amount of facilitator support they required; and d) the medium in which the facilitator support was provided. This approach allowed each parent to tailor TPOL-D to their particular individual circumstances on a week-by-week basis, effectively resulting in a 'minimal sufficiency' approach to intervention. It would be of benefit to further explore the impact of this flexibility of contact and to include different cultural settings.

# 4.3 Clinical implications

The study showed good results with the targeted population of parents and carers of children with mixed disabilities, demonstrating that it is possible to bring about significant change in parent-reported child behavior, parenting practices and parental self-efficacy for this demographic using a telehealth-based parenting intervention. Further, improvements achieved were either maintained or enhanced at 3-month follow-up, suggesting some durability of change. Parents in the TPOL-D were afforded flexibility in relation to both the amount and mode of facilitator contact they experienced throughout the program. It is suggested that this flexibility encouraged parents to engage with their support in a manner that was minimally sufficient to meet their individual needs, although further research specifically concentrating on this question is required in order to fully support this statement. In accordance with previous research (Sanders et al., 2012), participant satisfaction with the program was high, with all but two parents indicating that the program helped them deal more effectively with their child's problem behaviors. As TPOL-D can be facilitated by any practitioner who has been trained in Level 4 Stepping Stones Triple P (e.g., social workers, psychologists, doctors, counsellors, teachers, teacher aides and so on) the program is highly accessible at both an organisational and individual practitioner level.

#### 5. Limitations and future directions

A limitation of the current study was that the TAU group was provided with the intervention immediately post-completion of the T2 questionnaires. By their very nature online interventions imply an immediacy of treatment to registering parents. While the approach employed is ethically responsible (reducing a delay to treatment from 5 months to 2 months), it is acknowledged that the lack of a comparator group at T3 restricts the interpretation and conclusions that can be driven from follow-up outcomes. A further limitation of the study can be found in the range of disabilities represented which, while diverse, was clearly dominated by parents of children with ASD, with (13%) or without (69%) significant other co-morbid disabilities. While it was anticipated that this cohort would likely form the majority, a promotional 'push' by a peak ASD agency greatly increased representation of this group in the final (and largest) recruitment cycle. In future, it would be beneficial to evaluate TPOL-D with a greater range of disabilities – perhaps on a more 'targeted by disability' basis. It must also be acknowledged that the study data were provided through parent report and parents may have had expectations of improvement following their participation or, have experienced a desire to please their remote facilitator

and reported changes in outcome accordingly. While entry into the research study required diagnosis by a limited range of professionals, study constraints did not allow for confirmation of the primary diagnosis nor was the clinical severity of behavior problems objectively measured. The use of independent observers and measures with normative data and clinical cut-offs would be of benefit to future research.

While data in relation to the utility of the individual components of TPOL-D - including the SSTP Booklet and Handbook – was gathered and the use of these additional SSTP supports was discussed in therapist sessions, quantitative assessment as to use of the SSTP DVD and Handbook would have allowed for an evaluation as to how much difference these resources made in terms of parent-reported improvements. Future research should further explore the impact of each individual component of TPOL-D, including the utility of the SSTP resources specifically.

Finally, replicating across different cultural contexts and without therapist support would also be highly beneficial to support the effectiveness of the telehealth modality at a population health level. The results from this trial do however suggest that TPOL-D is a promising option for intervention for this population.

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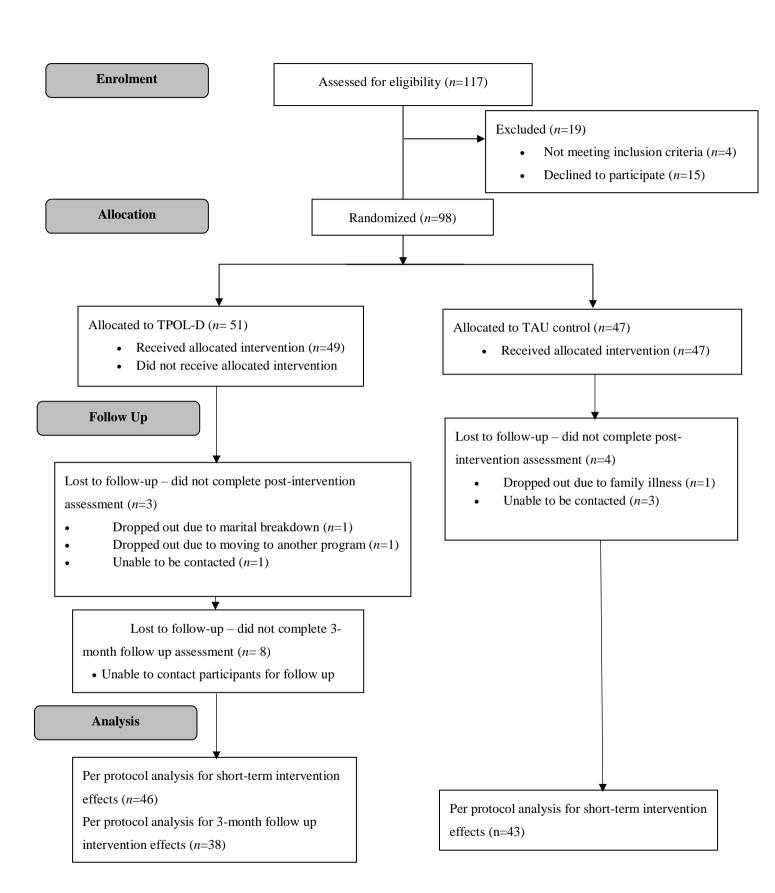
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**Figure 1**Flow of participants through the study

Sample characteristics of participants

5D  2.43  %  73 27  4 0 0 74 2 8 2 0 2 0 0 0 0 2	M 5.66  n 39 8 0 1 2 30 0 4 2 1 0 2 1	83 17 0 2 4 65 0 9 4 2 0	M 6.01  n 76 22  2 1 2 68 1 8 3 1	78 22 2 1 2 70 1 8 3	.91(1,9 χ2 1.53 1.62 <sup>b</sup>	.21
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84	43	92	86	88		
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<sup>&</sup>lt;sup>a</sup>ABI =Acquired Brain Injury, ASD = Autism Spectrum Disorder, Bind/VI = Blind/Vision Impaired, CP = Cerebral Palsy, DS = Down Syndrome, II/DD = Intellectual Impairment/Developmental Delay, LD = Language Delay/Language Disorder, SPD= Sensory Processing Disorder, OGCD= Other Genetic/Chromosome Disorder

<sup>&</sup>lt;sup>b</sup> Comparison of ASD v non ASD diagnosis

Table 2

Short-term intervention effects: intervention and TAU control conditions at pre- and post-intervention

Measure <sup>a</sup>	TPOL-D				TAU Control				<u>ANOVA</u>	р	$\eta_{p}^{2}$
	Preintervention Pos		Postinte	ostintervention Pro		Preintervention Po		rvention		1	ir
	M	SD	M	SD	M	SD	M	SD	F(df)		
DBC-P >4 Total <sup>b</sup>	63.79	32.91	56.21	34.32	60.46	28.04	60.03	25.0	3.69(1,76)	.058	.05
- Disruptive/Antisocial	21.60	11.96	19.33	12.66	19.16	9.79	18.79	9.37	1.35(1,76)	.25	.02
- Self-Absorbed	18.85	13.52	17.09	12.69	18.89	9.77	19.76	9.89	5.11(1,76)	.027	.06
- Comm. Disturbance	8.99	4.69	7.61	4.99	9.08	5.17	8.54	4.46	1.08(1,76)	.30	.01
- Anxiety	6.95	3.49	6.19	3.75	7.00	4.14	6.62	3.63	0.39(1,76)	.53	.001
- Social Relating	5.95	3.01	5.22	3.21	5.49	3.21	5.24	2.55	1.03(1,76)	.31	.01
CAPES-DD Total	20.02	8.24	18.46	7.51	19.81	6.53	18.39	6.36	.02(1.87)	.90	.00
- Emotional	2.13	1.61	1.87	1.73	1.53	1.78	1.65	1.67	1.66(1.87)	.20	.02
- Behavioural	13.11	7.53	11.67	6.54	13.42	5.88	12.06	5.54	.01(1,87)	.93	.00
CAPES-DD Self-Efficacy	81.24	21.93	97.30	20.08	79.42	18.86	79.88	20.72	13.33(1,87)	.000	.13
PAFAS Parenting Scale											
- Consistency	4.91	2.69	3.72	2.36	4.91	2.71	5.09	2.53	8.36(1,87)	.005	.09
- Coercive	4.69	2.34	3.35	2.06	4.53	2.68	4.63	2.89	12.39(1,87)	.001	.13
- Positive Encouragement	2.87	1.77	1.89	1.34	1.93	1.62	2.26	1.94	15.33(1,87)	.000	.15
- Parent-Child R'ship	2.37	2.43	1.61	2.19	2.28	2.50	2.39	2.74	5.62(1,87)	.020	.06

Note: F = ANOVA Time x Group effect; DBC-P = Developmental Behaviour Checklist - Primary Carer version; CAPES-DD = Child Adjustment and Parent Efficacy Scale – Developmental Disability; PAFAS = The Parenting and Family Adjustment Scales. Comm. Disturbance = Communication Disturbance. Parent-Child R'ship = Parent-Child Relationship.

<sup>&</sup>lt;sup>a</sup> Higher scores on all variables represent decreased functioning except for CAPES-DD Self-Efficacy scale where higher scores represent more positive behavior.

<sup>&</sup>lt;sup>b</sup>DBC-P intervention group n = 41 and TAU n = 37 due to exclusion DBC<4 parents (n = 5 Intervention, n = 6 control).

Table 3

Means and standard deviations (in parentheses) of the intervention group (n = 38) for all outcomes across time

Measure <sup>a</sup>	Pre-intervention	Post-intervention	Follow-Up	Significance
				T1 to T3
DBC-P >4 Total	63.79 (32.91)	56.21 (34.32)	44.74(26.82) <sup>b</sup>	p < .001
- Disruptive/Antisocial	21.61 (11.99)	19.33 (12.66)	15.69(11.03)	p < .001
- Self-Absorbed	18.85 (13.52)	17.09(12.69)	12.91(9.31)	p < .001
- Communication Disturbance	8.99 (4.69)	7.61 (4.99)	5.86(3.39)	p < .001
- Anxiety	6.95 (3.49)	6.19 (3.75)	5.00(3.26)	p < .005
- Social Relating	5.95 (3.01)	5.22 (3.21)	4.23(2.35)	p < .005
CAPES-DD Total	20.02 (8.20)	18.46 (7.51)	15.58(6.37)	p < .001
- Emotional	2.13 (1.61)	1.87(1.73)	1.21(1.28)	p < .005
- Behavioural	13.11(7.53)	11.67(6.54)	9.21(5.68)	p < .001
CAPES-DD Self-Efficacy	81.24(21.93)	97.30(20.08)	104.92(22.38)	p < .001
PAFAS Parenting				
- Consistency	4.91(2.69)	3.72(2.35)	3.05(2.28)	p < .001
- Coercive	4.69(2.34)	3.35(2.06)	3.26(1.88)	p < .001
- Positive encouragement	2.87(1.77)	1.89(1.34)	1.50(1.52)	p < .001
- Parent-Child relationship	2.37(2.43)	1.61(2.19)	1.53(1.96)	p < .005

<sup>&</sup>lt;sup>a</sup> Higher scores on all variables represent decreased functioning except for CAPES-DD Self-Efficacy scale where higher scores represent more positive behavior.

<sup>&</sup>lt;sup>b</sup>DBC-P T3 data n = 35 due to exclusion DBC<4 parents (n = 3).

## Chapter 6

# TPOL-D: Acceptability and parental satisfaction

Parenting a child with a disability presents many unique challenges that can impact on all aspects of family functioning (Reichman et al., 2008; Roux et al., 2013). Many parents who experience difficulties with their children's behaviours do not access professional support and parent participation rates remain a significant and ongoing challenge (Breitenstein et al., 2014; Sanders et al., 2014). While regular attendance at face-to-face parenting programmes undoubtedly presents a challenge for any parent, for parents of children with a disability barriers to in-person participation such as time, cost and logistical difficulties (Antonini et al., 2014; Breitenstein et al., 2014; Prinz & Sanders, 2007) are likely to be further exacerbated by the need for specialised and/or additional resources associated with caring for their child (Roux et al., 2013).

More accessible and cost-effective treatment options, such as telehealth and web-based interventions offer the potential of overcoming many of the barriers to participation inherent in 'traditional' in-person delivery modalities (Wainer & Ingersoll, 2015), facilitating the completion of training at a time, place and pace that is convenient to the needs of the parent and their families (Breitenstein et al., 2014). Importantly, the use of telehealth technologies for intervention delivery offers much more than just flexibility and convenience. The rise of the Internet, when paired with the ever-increasing sophistication of multi-media technologies, offers the ability to create highly interactive and individualised telehealth interventions, structured in a manner that ensures both standardisation of delivery and fidelity of implementation (Baggett et al., 2010).

While the controlled evidence remains limited, comparisons of telehealth parenting interventions with conventional face-to-face therapy have not only shown comparable outcomes in treatment results but have also indicated that online programmes deliver parenting support in a manner that overcomes many of the traditional barriers to support (Daneback & Plantin, 2008; Enebrink et al., 2012; Nieuwboer et al., 2013a; Sanders et al., 2012) while maintaining high levels of client satisfaction (Antonini et al., 2012; Day, 2016; Ingersoll & Berger, 2015; Nieuwboer, Fukkink, & Hermanns, 2013b; Vismara, McCormick, Young, Nadhan, & Monlux, 2013) and therapeutic alliance (Wade et al., 2011).

While telehealth parenting interventions show great promise, further investigation is needed not only into the efficacy of such interventions, but also the feasibility of and parent engagement and satisfaction with these programmes. The current study explores the acceptability of and parental satisfaction with Triple P Online – Disability (TPOL-D), a novel telehealth parenting intervention targeting parents of children with a disability aged 2-12 years. More specifically, research questions addressed: (1) intervention adherence; (2) overall satisfaction with TPOL-D; (3) therapist identification and alliance; (4) perceived helpfulness of the individual components of TPOL-D; (5) 'useability' of online modules; and (6) future consumer preference and advocacy issues. Given that no in-person contact occurs at any time between the participating parent and the therapist in TPOL-D (or any other person involved in the research) the exploration of parents' perceptions in relation to therapist contact were considered of particular interest in the present study.

#### Method

## Study design

A previous study (Hinton, Sheffield, Sanders & Sofronoff, 2017) employed a randomised controlled trial following a 2 group (TPOL-D vs treatment-as-usual [TAU] control) x 3 time (pre-intervention [T1], post-intervention nine-weeks after initial login [T2], and three-month follow-up [T3]) repeated measures design. Randomisation was achieved using an online computer programme (www.randomization.com). The current study focuses on the satisfaction and acceptability data obtained from the intervention group at T2, i.e. immediately post intervention.

## **Participants**

Ninety-eight parents of children with a disability aged between 2 and 12 years were recruited to participate in the intervention. Of these, 51 parents were allocated to the intervention group with 46 parents completing the Time 2 efficacy questionnaires. Due to a user error, one parent in the intervention group did not complete the satisfaction questionnaires, reducing the sample size (n = 45) in all outcomes except for intervention adherence (n = 46). No limitation was placed on the nature of the child's disability; however, inclusion criteria required diagnosis from a Neurologist, Psychiatrist, Psychologist, Speech Pathologist or Occupational Therapist, as well as child age between 2 and 12 years (at point of recruitment). Parents were encouraged to work through the intervention with a partner, family member or friend however only one parent per family was asked to complete questionnaires.

#### **Procedure**

Ethical approval for the project was obtained from the University of Queensland in accordance with National Health and Medical Research Council of Australia standards; ethics approval number 2012001065. Australia-wide recruitment was conducted over a 12-month period via community outreach in mass media, disability support associations, support groups and schools with a Special Education Unit (Queensland only). Post email inquiry, parents were forwarded a detailed information flyer outlining the programme structure, content, timings and technology requirements - along with a link that allowed them to review the online programme interface. Parents were informed the programme was being offered with staggered start dates throughout the year and that each 'cycle' would have two possible start dates for which they would need to be available. One week prior to commencement of each cycle of the intervention, interested parents were invited to complete online registration and informed consent, as well as their T1 questionnaires. Post-completion, parents were emailed their TPOL-D commencement date, with the intervention group also receiving their individual log-in details, personalised timetable and supplementary disability-specific resources (via registered mail). Participants allocated to the TAU control group were also emailed information in relation to their (later) programme start date and T2 questionnaire timings. To guarantee consistency in the intervention approach, the first author (Masters qualified, SSTP-accredited psychologist) was the remote facilitator for all intervention participants.

#### **Intervention**

Triple P Online-Disability (TPOL-D) is a telehealth variant of the Triple P-Positive Parenting Program (Triple P; Sanders, 2012). Targeting parents of children (aged 2-12 years) with mixed disabilities, TPOL-D combines elements of the evidence-based Triple P Online (TPOL; Turner & Sanders, 2011) and Stepping Stones Triple P (SSTP: Sanders, Mazzucchelli, & Studman, 2004) programmes, with several unique variations.

Level 4 Triple P is an intensive training programme of 8-10 sessions for parents of children with more severe behavioural difficulties. A web-based version of Level 4 Triple P – Triple P Online (TPOL; Turner & Sanders, 2011) has been developed, with empirical trials showing promising results (Day, 2016; Love et al., 2016; Sanders et al., 2014; Sanders et al., 2012). Delivered via the internet, TPOL consists of eight, self-directed modules providing instruction in the use of 17 core positive parenting skills. Topics covered include: (1) What is

positive parenting?; (2) Encouraging behavior you like; (3) Teaching new skills; (4) Managing misbehaviour; (5) Dealing with disobedience; (6) Preventing problems by planning ahead; (7) Making shopping fun; and (8) Raising confident, capable kids. The web-based modules are guided by a therapist (Professor Matt Sanders) talking to camera as if talking directly to parents – in effect acting as a 'virtual' therapist (Refer Figure 6.1).

Figure 6.1. Screenshot of virtual therapist (Professor Matt Sanders)



Completed in sequential format (i.e., module completion opens access to the next module), the interactive programme includes video-based modelling of parenting skills, parent-driven branching to review or gain information, personalised goal setting and probes

and exercises to assist parents in checking mastery. Given its promising evidence base and ready online accessibility, TPOL was adapted as the foundation programme for TPOL-D.

While another variation of Triple P – Stepping Stones Triple P (SSTP; Sanders, Mazzucchelli, & Studman, 2004) – has been specifically developed and trialled for parents of children with a disability, the programme is not available in an online format. Notably, SSTP delivers the same information and module sequencing as that found in Triple P and TPOL, but 'extends' learnings to incorporate unique disability-specific information and strategies. Further, the visual content and imagery in SSTP focuses on children with disabilities, rather than typically developing children. As SSTP has previously been evaluated with children with mixed disabilities such as Down syndrome (Roberts et al., 2006), cerebral palsy (Whittingham et al., 2014), autism spectrum disorders (Whittingham et al., 2009); and acquired brain injury (Brown et al., 2014), the incorporation of the unique disability-specific content and visuals covered in SSTP (but missing from TPOL) was considered essential when creating TPOL-D. To achieve this in an economically-viable manner, two companion, hard-copy resources were provided to all intervention parents (a DVD - SSTP: A survival guide for families with a child who has a disability and a handbook - SSTP: A guide to positive parenting), with the pertinent content from these resources being synchronously programed for delivery with the relevant weekly TPOL web-based module.

With the success of any parenting programme depending on both the willingness of parents to engage, as well as the feasibility of such engagement (Love et al., 2013), the final stage in developing TPOL-D involved focus group consultation to assess consumer preferences with respect to telehealth-based parenting programmes, including any desired additional supports. Using a web-based, questionnaire link (SurveyMonkey), disseminated via relevant support agencies on an Australia-wide basis, 101 responses from eligible parents and carers of children (aged 0-17 years) were received between March and July 2014. Drawing upon the consumer-preference information received, several novel variations were incorporated into TPOL-D.

The first of these variations was the inclusion of an optional, weekly telephone or email session, with a SSTP-accredited facilitator. This contact provided an opportunity for parents to clarify module content, gain assistance in customising strategies and engage in supported problem solving regarding both family and disability-specific concerns. Sessions were scheduled to occur at the same time each week, with parents strongly encouraged to complete their weekly online module and hard-copy readings prior to facilitator contact.

With the exception of two Australian parents temporarily residing overseas (Sweden and USA), consultation times were initially scheduled as a telephone call, however participants were subsequently advised in their Week 1 contact that facilitator support could be accessed via telephone or email. Parents were also offered the opportunity to email prior to their weekly appointment if they did not require facilitator contact in any week. In combination, these variations provided significant flexibility in relation to both the type and amount of facilitator support parents received – with control of these features residing with the parent.

A further support incorporated into TPOL-D based on focus group feedback was a private Facebook 'parent support group'. With the sole purpose of facilitating intra-parent contact, inclusion in the group was optional with interested parents being added by the administrator upon entering Week 1 of the intervention. No additional content in relation to TPOL-D was provided in this group, however reminders in relation to questionnaires being due were posted. The site was monitored by the facilitator (administrator) and notices posted in relation to relevant community events and activities.

A final support added to TPOL-D was personalised timetables, which were emailed to all participants upon intervention allocation. These simple 'visual schedulers', provided week-by-week guidance as to programme expectations and content deliverables including module completion dates, additional disability-specific DVD/handbook learnings and scheduled appointment times. These were discussed in weekly facilitator sessions to help parents track their progress through the modules and hard-copy content.

The unique, but somewhat hybridised, nature of the current intervention, it's content and delivery formats was recognised in the naming of the intervention as TPOL-D.

### **Research questions**

While the main focus of the trial of TPOL-D was to evaluate the efficacy of the programme for parents with children with a developmental disability, the use of a consumer-perspective to drive TPOL-D's development also raised a number of questions. These questions largely centre around the feasibility and acceptability of the delivery mode itself and include the following:

- 1. Does the programme meet the needs of parents who decided to participate i.e. are these parents satisfied with what they received.
- 2. Are parents who never meet a face-to-face therapist able to form a working relationship with that therapist and/or with the therapist featured in the online programme?

- 3. Which components of TPOL-D do parents find most useful in working through the intervention?
- 4. Did parents consider TPOL-D easy to access, intuitive and engaging?
- 5. Having completed a telehealth parenting programme would parent-consumers: (a) re-engage with the telehealth modality themselves in future; and (b) advocate to other parents in relation as to the utility of TPOL-D?

### **Outcome measures**

Prior to commencing the intervention, all parents completed a demographics measure that provided information in relation to themselves and their child as well as measures relevant to hypothesised child and parent outcomes – see also Hinton et al., (2017). Immediately post-intervention parents completed the following questionnaires pertaining to the intervention.

Client Satisfaction Questionnaire (CSQ; Sanders et al., 2010). Client satisfaction was assessed using the Client Satisfaction Questionnaire at post-intervention for the intervention group only. The 13-item measure evaluated satisfaction on a range of indicators such as the quality of the service, the extent to which the programme met the needs of the family, and whether parents feel the programme has equipped them to deal more effectively with problems that arise. Items are rated on a scale of 1 to 7, and a total score ranging between 13 and 91 is obtained by summing the items, with higher scores indicating greater satisfaction with the programme. The scale has high internal consistency ( $\alpha = .96$ ) (Sanders, Markie-Dadds, Tully, & Bor, 2000).

Working Alliance Inventory – Short Revised (WAI-SR; Hatcher and Gillaspy, 2006). The working relationship or 'therapeutic alliance' between client and therapist has long been established as a universal agent of change, and is a significant predictor of treatment outcomes. The Working Alliance Inventory-Short Revised (WAI-SR) is a refined 12 item measure of the therapeutic alliance that assesses three key aspects of the therapeutic alliance: (a) agreement on the tasks of therapy, (b) agreement on the goals of therapy; and (c) development of an affective bond. Clients rate items on a 5-point Likert scale (range: 1 – Rarely or Never to 5 – Always), with higher scores indicating a better therapeutic alliance. A Total score can be calculated as a mean of all 12 items. Internal consistency scores (coefficient alphas) ranging from .91 to .92 for the total WAI-SR score, .85 to .87 for Goals, .85 to .87 for Tasks, and .85 to .90 for Bond have been reported (Hatcher and Gillaspy, 2006).

**Utility of Individual TPOL-D Component Questionnaire.** Consisting of 5 questions, this questionnaire used a 5-point likert scale (range: 1 – Did not use to 5 – Essential) to rate the perceived helpfulness of the resources used to deliver TPOL-D.

**Ease of Use TPOL Web-based Modules Questionnaire**. Consisting of 8 questions, this questionnaire used a 5-point likert scale (range: 1 – Strongly disagree to 5 – Strongly agree) to rate the functionality of the TPOL modules.

Additional questions were incorporated to assess participants': (a) perceptions in relation to their therapist; and (b) preferred modality of accessing future parenting programmes.

#### **Results**

# Preliminary analyses

A total of 46 parents completed TPOL-D and the post-intervention assessment measures in the Intervention condition. Where applicable, results indicate incomplete data though the provision of a denominator when nominating sample size. Chi-square analyses were conducted to examine potential differences between 'completing' (n = 46) and 'non-completing' (n = 5) parents. No significant differences were found between the groups on any demographic variable, including age or gender (of the child with a disability), marital status, employment status or family composition (of the participant parent). Participant demographics and completion status are provided in Table 6.1.

Table 6.1. Sample characteristics of participants

Variables	-		Non-c	Non-completer	
	n = 46		n	n = 5	
	M	SD	M	SD	
Child age (years)	6.41	2.39	5.60	2.97	
	n			n	
Gender of child					
Male	34			3	
Female	12 2		2		
Diagnosis <sup>a</sup>					
ABI + ASD + Epilepsy	2			0	
ASD	35			3	
ASD + CP + Dispraxia	1			0	
ASD + II/DD	3			1	
ASD + OG/CD	1			0	
Cornelis de Lange syndrome	0			1	
II/DD	1			0	
Prader Willi syndrome	2			0	
Williams syndrome	1			0	
Participant Relationship to Child					
Mother (biological or adoptive)	38			5	
Stepmother	2 0		0		
Foster Mother	1 0		0		
Father (biological or adoptive)	4 0		0		
Grandmother	1		0		
Marital Status					
Married/Defacto	32 2		2		
Cohabitating	6 1		1		
Divorced/Separated	7 1		1		
Single	1		1		
Family Composition					
Original	35		2		
Step-family	4			1	
Sole Parent	5			2	
Foster Family	1			0	
Extended	1 0		0		
Employment – Participant Parent					
Full Time (35hrs+)	10 0		0		
Part-Time/Casual	13 2		2		
Employed (on maternity leave)	1 0		0		
Full Time Student	2			2	
Unemployed	20 1		1		

 $<sup>{}^</sup>aABI = Acquired\ Brain\ Injury,\ ASD = Autism\ spectrum\ disorder,\ II = Intellectual\ impairment/Developmental\ delay,\ OG/CD = Other\ Genetic/Chromosome\ disorder.$ 

 $<sup>^{\</sup>rm b}$  Comparison of ASD v non ASD diagnosis.

#### **Intervention adherence**

On average, parents in the TPOL-D group (n = 51) completed seven of the online modules (SD = 2.16; range 0 to 8). Two parents (4%) did not actively engage with the online intervention, defined as either not logging in at all, or logging in briefly but not completing the first module. Parents participated in an average of six weekly telephone or email consultations with their remote facilitator, with 80% of these being completed by telephone and 20% by email. Twenty-six parents used a mixture of telephone and email consultations, with two parents using email contact only. Overall, there was good adherence to TPOL-D with 90% (n = 46) of parents engaging with the intervention and completing Time 2 assessment measures.

#### Parent satisfaction with TPOL-D

As measured by the CSQ, parents in the intervention group reported high levels of satisfaction with TPOL-D, with a mean Total Score of 73.49 out of 91 (SD = 11.36). Ninety-six percent of participants rated the quality of service they received as 'good' to 'excellent' (n = 43) with 96% of participants also indicating TPOL-D had helped them to deal more effectively with their child's behaviour (n = 43) (Refer Figures 6.2 and 6.3).

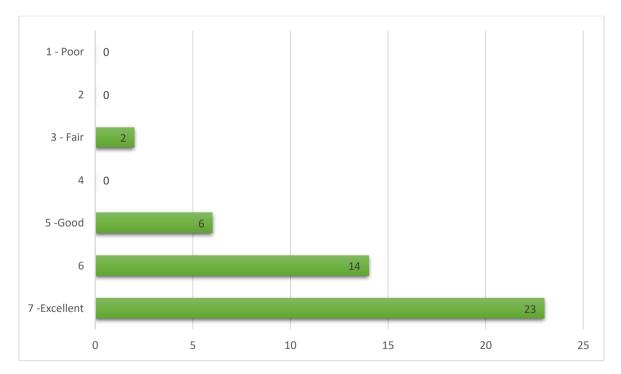
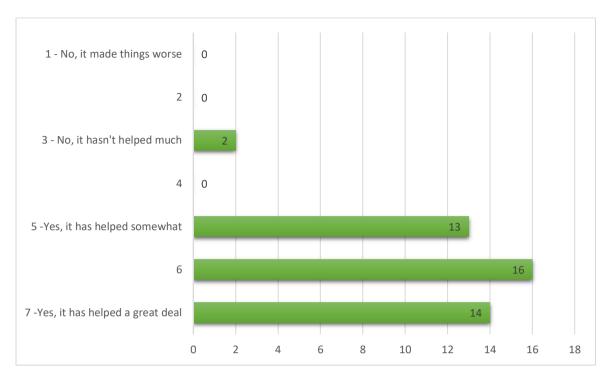


Figure 6.2. Parent ratings of quality of service received



**Figure 6.3.** Parent ratings as to whether TPOL-D assisted them in managing their child problem behaviour

Ninety-one percent of parents (n = 41) indicated that they received the: (a) type; and (b) amount of help that they wanted from TPOL-D, with 98% (n = 44) reporting a global sense of satisfaction with TPOL-D (refer Figures 6.4 – 6.6).

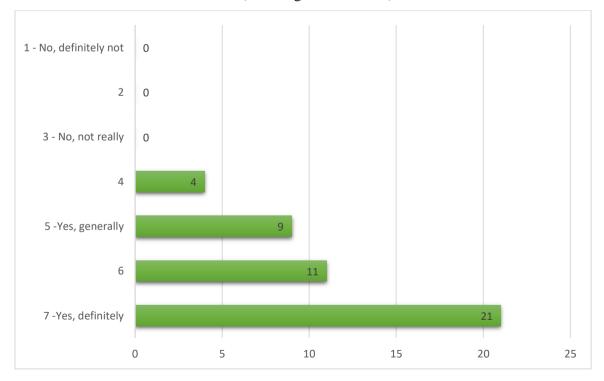


Figure 6.4. Participant satisfaction with type of help received

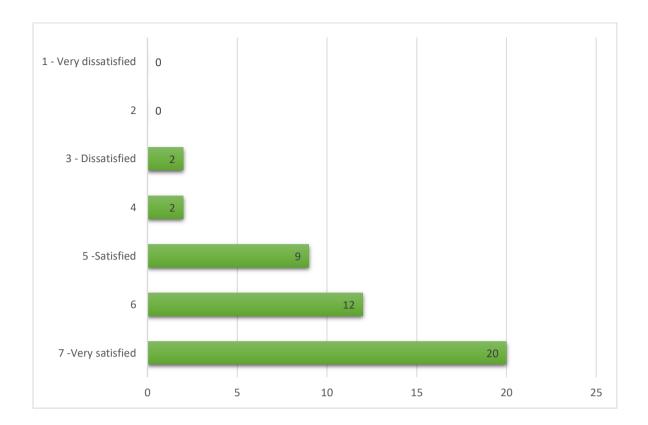


Figure 6.5. Participant satisfaction with amount of help received

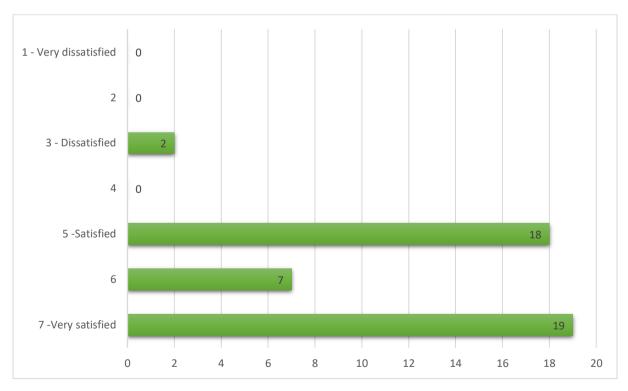


Figure 6.6. Global sense of satisfaction with TPOL-D

### Therapist identification and utility of therapist contact

In the delivery of TPOL-D, no in-person contact occurred at any time between the participating parent and the therapist (or any other person involved in the research). Parents had weekly access to a remote therapist by phone or email, while TPOL modules were guided by a virtual therapist. Notably, 100% of parents (n = 45) indicated that they felt they had the support of a therapist during TPOL-D, with 69% (n = 31) of parents identifying with their weekly telehealth therapist alone and 31% (n = 14) identifying with both the remote and virtual therapist.

When asked more specifically about the 'helpfulness' of the remote therapist support, 96% of parents (n = 43) reported that the weekly contact with a telehealth therapist; (a) helped answer questions they had about the online content; (b) provided additional support in completing the intervention; and (c) helped them stay on track with the programme.

Parent ratings using the WAI-SR reinforced these qualitative findings, with Task ( $\overline{x}$  = 4.19,  $\sigma$  = 1.19), Bond ( $\overline{x}$  = 4.40,  $\sigma$  = 0.32) and Goal ( $\overline{x}$  = 16.7,  $\sigma$  = 2.96), as well as the Total score ( $\overline{x}$  = 4.26  $\sigma$  = 0.26) lending support to the development of a positive therapuetic bond between parents and their remote therapist, despite the lack of any in-person contact at any time.

#### Utility of individual components of TPOL-D questionnaire

Using a scale of 1 (Did not use) to 5 (Essential) parents were asked to rate how 'helpful' they found each component of TPOL-D when completing the intervention. While weekly therapist contact ( $\overline{x} = 4.4$ ,  $\sigma = .78$ ) received the highest rating of helpfulness, every resource was reported as being 'essential' by a minimum of 2 parents. Table 6.2 provides the mean rating scores and standard deviations for each TPOL-D component.

Notably, while initially considered more of a time-tracker than a formal component of TPOL-D (and therefore not included in the components questionnaire), related research on the RCT (Hinton et al., 2017) identified the weekly personalised timetable as being an essential component (i.e. visual scheduler) of the TPOL-D intervention, e.g. 'I found that if I applied the strategies and followed the weekly timetable, I found that stress was minimised and since everything was visually displayed to me, it was easier to follow the steps'; '...the timetable is awesome for staying organised and on track'; 'The timetable kept me on top of

the programme and helped me to organise my time around completing each section of the modules'.

**Table 6.2.** Perceived 'helpfulness' of individual TPOL-D components

Resource	M (Range 1-5)	SD	Essential Resource (n)
Weekly therapist contact	4.40	.78	23
Online modules <sup>a</sup>	4.00	1.56	15
SSTP Booklet	3.47	.94	3
SSTP DVD	3.09	1.18	3
Facebook Group	2.00	1.22	2

 $<sup>\</sup>overline{a}n = 44$ 

# Ease of use TPOL web-based modules questionnaire

As illustrated in Table 6.3, participants responded positively to the functionality of the TPOL modules indicating that the site was easy to access ( $\bar{x} = 4.34$ ,  $\sigma = .78$ ), intuitive in nature ( $\bar{x} = 4.41$ ,  $\sigma = .79$ ) and enjoyable to use ( $\bar{x} = 4.14$ ,  $\sigma = .76$ ). From a content delivery perspective, participants believed that they had learned the material presented on the site ( $\bar{x} = 4.49$ ,  $\sigma = .59$ ). With a maximum possible score of 5, only one item – 'The site loaded quickly on my computer' – achieved a mean score below 4.1. This response reflected issues reported by several participants in relation to lags in module load time throughout the course of the intervention as well as issues with using the intervention on a particular operating system.

**Table 6.3.** Means and standard deviations for participant perceptions re 'ease of use' of TPOL online modules (n = 44)

Question	M	SD
	(Range 1-5)	
1. The site was easy to access.	4.34	.776
2. The site loaded quickly on my computer	3.50	1.21
3. I found it easy to navigate through the site	4.41	.787
4. Using the site was intuitive	4.36	.78
5. The language of the site was appropriate for me	4.57	.76
6. I was motivated to explore most of the site	4.18	.84
7. I enjoyed using the site	4.14	.76
8. I believe I learned the material on the site	4.49	.59

#### Consumer advocacy and future participation in parenting programmes

Upon completing the online parenting programme, parents were asked to explore their current feelings about the utility of such interventions. Ninety-eight percent of parents (n = 43/44) indicated that they would recommend undertaking Triple P Online to other parents and carers. When asked what their future 'first preference' would be in undertaking a parenting programme 58% of parents (n = 26) indicated that they would participate in an online modality only, while 42% (n = 19) indicated that they would be equally happy to participate in an online or face-to-face modality in future. Issues of time, convenience and resources were widely cited as the main drivers for an online preference e.g.; 'It is impossible for me to get away to attend a face-to-face programme'; 'Our personal circumstances make it difficult to find care for our children'; 'It is easier to do it online as I can work around the kids'. Lack of personal stigma was also mentioned as being a driver to participation (e.g.,; 'Not so personally confronting'; 'Easier to take parenting help from a faceless source'; 'Able to reflect more accurately and take the time to admit to myself the depth of the problems that I may be unwilling to admit to an actual person').

#### Discussion

In their meta-analysis of technology-assisted interventions for parents, Hall and Bierman (2015) suggested that the strongest effects in terms of both engaging parents and promoting positive outcomes may result from blended intervention approaches that incorporate the use of technology along with synchronous communication from professionals (e.g. phone calls, video chat and so on). This study examined the acceptability of such a blended intervention – Triple P Online-Disability. Overall, parents reported a high degree of satisfaction and engagement with TPOL-D, with a very small attrition rate (10%) being observed across the course of the intervention. Most importantly, parents also indicated that TPOL-D provided them with the type and amount of help they wanted.

Despite the lack of in-person contact in TPOL-D, 100% of parents who completed the intervention felt they had the support of a therapist, with 69% of these parents identifying the weekly telehealth therapist and 31% identifying both the weekly telehealth as well as the virtual therapist as their therapist for the intervention. As a substantial evidence base exists to suggest therapeutic alliance plays an important role in enhancing treatment outcome in a variety of therapies (Anderson et al., 2012; Schmidt, Chomycz, Houlding, Kruse, & Franks, 2014; Sucala et al., 2012) the finding that 100% of participating parents identified with the remote therapist as their personal therapist for TPOL-D, despite never having met or even seen her in 'real life', is promising.

While all components of TPOL-D received a rating as an 'essential resource', weekly therapist contact, online modules and the SSTP Booklet were identified as the most helpful of the individual TPOL-D components. With research in telehealth-based behavioural interventions indicating that even brief therapist support increases treatment adherence (Mohr et al., 2011) as well as efficacy (Palmqvist et al., 2007; Spek et al., 2007) it is perhaps not surprising that weekly therapist contact was considered the most 'helpful' of the individual components of TPOL-D, as it gave parents the opportunity to personalise the content learnt in the online modules to the particular needs of their child with a disability.

Irrespective of any technical issues encountered, parents indicated that the TPOL modules were enjoyable to use, rating them highly in terms of useability, intuitiveness and ease of access. Many parents engaged with the modules at times that would not commonly be available to in-person parenting training programmes (i.e. very early morning, very late evening) and this convenience and flexibility of access was widely cited as being a main driver to completing parenting interventions in an online modality. With parents encouraged

to access the online module and hard-copy resource content prior to their weekly therapist contact, these sessions were able to be used to assist parents in personalising strategies and skills to the (often very specific) needs of their child with disability.

The final area of evaluation asked parents to consider their perceptions and preferences in wake of having completed a telehealth parenting programme. When questioned as to their future 'first preference' for undertaking a parenting programme, 58% of parents indicated that they would participate in an online modality only, while 42% indicated that they would be happy to participate in online or in-person interventions in future. All but one parent (98%) indicated that they would recommend undertaking TPOL/TPOL-D online to other parents and carers. In their 2012 paper, Sanders and Kirby (2012) argue that a strong consumer perspective is required to ensure interventions are not only responsive to the preferences and needs of families but also that they result in increased population reach. Having adopted a consumer-perspective approach to the development of TPOL-D (refer Chapter 3) these findings are highly encouraging as they suggest that there was minimal mismatch between the expectations that parents held in relation to TPOL-D and the reality of the intervention.

The current research has a number of limitations. The study reflects a relatively small sample size and no investigation as to 'comfort with technology' was undertaken prior to research participation. The lack of standardised measures makes it difficult to know how well the results would generalise to other families. While satisfaction with individual components of the intervention was assessed, in hindsight the omission of the personalised timetable (i.e. visual scheduler) as a component of TPOL-D was a limitation. Additional research is needed to investigate other factors that contribute to the satisfaction and feasibility of the current intervention. For example, was satisfaction with the intervention moderated by remote therapist characteristics, family or child characteristics (e.g., type and severity of disability), or parents' experience with technology? In addition, are there components of TPOL-D that could be removed or scaled down without significantly affecting caregiver satisfaction?

#### Conclusion

The present study explores the acceptability of and parental satisfaction with Triple P Online – Disability (TPOL-D), a novel telehealth parenting intervention targeting parents of children with a disability aged 2-12 years. Overall, parents reported high levels of satisfaction with TPOL-D and responded positively to the functionality of the web-based modules. While additional research is required to determine whether the same results occur

with larger samples and/or modified intervention components, the results from this trial suggest that TPOL-D is a promising intervention for parents of children with a disability.

## Chapter 7

#### General discussion and conclusions

The concluding chapter of this dissertation provides a summary of the findings reported within this thesis, followed by a discussion of the limitations within the programme of research and some suggestions for addressing any such limitations in future.

The primary aim of this thesis was to develop and investigate the efficacy of a telehealth-based parenting intervention (TPOL-D) for a specific population of parents – those who have children with a disability aged between 2 and 12 years. With no limitation being placed on the nature of the child's disability, TPOL-D's mixed disability focus is (to the author's knowledge) unique in the literature of telehealth-delivered parenting interventions. The acceptability of and parent satisfaction with TPOL-D was also examined as a secondary outcome – providing a consumer-parent perspective on a number of issues relevant not only to the evaluation of TPOL-D itself, but also to future research in this area. For the sake of clarity and replicability, the steps taken in developing, delivering and evaluating TPOL-D have each been detailed in a dedicated chapter.

#### **Key findings**

1. There is a paucity of research into evidence-based telehealth interventions for parents of children with a disability and this is an important area for future empirical attention.

The systematic review presented in Chapter 2 examined the current state of the evidence base for online/telehealth parenting interventions for parents of children with a disability aged 0-17 years. A systematic search of seven databases revealed a small number of studies (three RCTs and two pre-post studies) specifically focusing on online parenting programmes for parents and carers of children with a disability in this age group. These results indicated the distinct lack of research in this area. Given there is convincing evidence attesting to the benefits that parents and children derive when parents learn positive parenting skills (Sanders, 2012) and further, that in the absence of appropriate and timely supports the many unique challenges that families of children with disabilities will experience are likely to escalate (Families Special Interest Research Group of IASSIDD, 2014), increasing access to evidence-based parenting support for this population is a priority. Telehealth interventions offer such promise and empirical attention to this area is required.

# 2. Knowledge of consumer preferences may facilitate the development of effective telehealth interventions that are not only accessible but also acceptable to the needs of the target population.

The development of evidence-based parenting interventions that not only appeal to parents but are also compatible with their needs in terms of delivery format and content have the potential to produce better population reach as well as delivery of interventions in the most cost-effective and efficient manner possible (Metzler, Sanders, Rusby & Crowley, 2012). Chapter 3 used a qualitative survey methodology to investigate technology use in a sample of 97 parents and carers of children with a disability (aged 0 – 17 years). The acceptability of telehealth-based parenting interventions for this population was also explored, along with the perceived utility of a range of resources for potential inclusion in the delivery of such training. Results indicated that telehealth delivered parenting programmes were acceptable, even desirable, to the target population of parents with strong preferences being expressed as to the type and nature of supports desired by this population in the delivery of such an intervention. The results from this survey were used to develop the components of a novel telehealth parenting intervention, Triple P Online – Disability (TPOL-D).

Post-delivery of TPOL-D, the utility of the components of the intervention, as well as the intervention itself, were re-explored to assess the acceptability of and consumer satisfaction with TPOL-D, as reported in Chapter 6. The 'match' between what consumer-parents stated they desired in a telehealth parenting intervention and their use of these components will be further explored in Key Finding 3b, below.

# 3. Conclusions regarding TPOL-D: Efficacy, acceptability and satisfaction

Building from the previous findings, a further aim of this thesis was to determine the efficacy of a telehealth-delivered behavioural family intervention (TPOL-D). A scientific protocol for an RCT was written to ensure transparency of process (Chapter 4). The RCT was conducted according to the guidelines of the protocol and results have been presented for primary outcomes of: (1) parent-reported child behavioural and emotional problems; and (2) parenting skills and self-efficacy (reported in Chapter 5) and secondary outcomes of: (1) intervention adherence; (2) overall satisfaction with TPOL-D; (3) therapist identification and alliance; (4) perceived helpfulness of the individual components of TPOL-D; (5) 'useability' of online modules: and (6) future consumer preference and advocacy issues (reported in Chapter 6). To the author's knowledge the current research represents the first RCT of a

telehealth based behavioural intervention for parents of children with mixed disabilities, providing an important contribution to the growing literature available in this area.

#### 3a. Efficacy of TPOL-D in improving parent and child outcomes

As reported in Chapter 5 and, contrary to expectations based on similar research in both telehealth delivered parenting programmes (Sanders et al., 2012; Wade, et al, 2005b; Wade et al., 2006a; Wade, et al, 2009) and parenting programmes for parents of children with a disability (Brown et al., 2014; Roux et al., 2014; Whittingham et al., 2009), TPOL-D parents did not report a significant decrease in child behaviour problems immediately post intervention in comparison with the TAU control group. However, re-examination of this key outcome at T3 (3-months post intervention completion) not only indicated that the DBC-P total score had fallen below the clinical cut-off for child behavioural and emotional problems, but that within-subjects analysis showed a large effect, globally ( $\eta_p^2 = .47$ ), and at individual scale level: DBC-P Total Behaviour Problem scale ( $\eta_p^2$  = .46) and Capes-DD Total Problems scale ( $\eta_p^2 = .31$ ). Considered together, these results indicate that parent-reported child behavioural and emotional problems significantly decreased from T1 to T3. While caution is required in interpreting this result further - given the lack of a comparator group at T3 - it is important to note that parents in the TPOL-D group did not report undertaking any other parenting intervention in the 3-month follow up period. As such, this result potentially suggests the presence of a sleeper effect for this outcome.

Consistent with existing trials in both online and in-person parenting programmes for children with a disability (Mast et al., 2014; Roux et al., 2013; Sanders et al., 2012; Wade et al., 2005a; Wade et al., 2006b; Wade, Karver et al; 2014) a significant large effect was reported for both parent-reported self-efficacy ( $\eta_p^2 = .13$ ), as well as parenting style ( $\eta_p^2 = .22$ ). Within-subjects analysis undertaken at 3-months post intervention continued to support significant large effects for both self-efficacy ( $\eta_p^2 = .49$ ) and parenting style ( $\eta_p^2 = .5$ ), indicating that these improvements were maintained, if not improved, over time. These findings lend support to the potential durability of these changes.

#### 3b. TPOL-D: Acceptability and satisfaction

As reported in Chapter 6, TPOL-D enjoyed good intervention adherence with a 90% completion rate. From a technological perspective, parents indicated that the online modules were enjoyable to use, rating them highly in terms of useability, intuitiveness and ease of acces. Globally, parents reported high levels of satisfaction with TPOL-D, indicating that

they received the nature and amount of support they desired from the intervention, and that they believed that TPOL-D had helped them deal more effectively with their child's behaviour. Weekly therapist contact, online modules and the SSTP booklet were identified as the most helpful of the individual TPOL-D components, although all included components received a rating as an 'essential resource' from a minimum of two parents.

With a substantial evidence base in existence to support the role that therapeutic alliance plays in enhancing treatment outcome in a variety of therapies, including parenting programmes (Kazdin & Whitley, 2006; Schmidt, Chomyz, Houlding et al, 2014), the finding that 100% of participating parents identified with the remote therapist as their personal therapist for TPOL-D, despite the absence of face-to-face contact, was promising. It is also notable that 31% percent of parents also identified the virtual facilitator (Professor Matt Sanders) as being their therapist, despite the non-interactive nature of this relationship. This outcome warrants further exploration.

Parents indicated that the weekly therapist contact: helped answer questions; provided additional support; and helped them stay on track. Findings from the WAI-SR supported the forming of a strong therapeutic alliance (Task [ $\bar{x}$  = 4.19,  $\sigma$  = 1.19], Bond [ $\bar{x}$  = 4.40,  $\sigma$  = 0.32] and Goal [ $\bar{x}$  = 16.7,  $\sigma$  = 2.96]) between parents and their remote therapist. Finally, 100% parents who completed TPOL-D indicated that they would undertake a teleheath-delivered parenting itnervnetion again, with all but one parent also indicating that they would recommend undertaking TPOL-D to other parents and carers.

Given the consumer-perspective approach taken to developing TPOL-D, the findings from the parent acceptability and satisfaction outcome data detailed in Chapter 6 are of interest from the perspective of examining the degree of compatibility between the components and supports a sample of parent-consumers of children with a disability believed they would like included in a telehealth-delivered parenting intervention (as detailed in Chapter 3) and the perspective of a group of comparable parent-consumers who actually undertook and completed such an intervention (as detailed in Chapter 6). Similar research linking these two perspectives in one study was unable to be located, indicating that the results presented in this thesis add a novel perspective to the research previously undertaken in this field. The high levels of satisfaction expressed with TPOL-D suggest the consumer-perspective of the parents who undertook the survey with respect to the components they would like in a telehealth-delivered intervention matched the consumer expectations of the

parents who actually undertook the intervention. This outcome would benefit from further exploration in future studies.

# **Clinical implications**

The applied nature of this research means that it has clear implications for clinical practice. Given the high rate of behavioural and emotional difficulties occurring in children with disabilities (Einfeld & Tonge, 1996) and the impact that these maladaptive behaviours can have not only on the children themselves but also on their parents, families and the broader community (Roux et al., 2013), it is vital to develop evidence-based interventions for parents and caregivers of these children that are not only effective but also accessible and engaging. The current dissertation explored a telehealth parenting intervention developed with input from consumers as to their preferred formats for receiving information and support. Results demonstrated that it is possible to bring about significant change in parenting practices and parental self-efficacy for this demographic using a telehealth-based parenting intervention. While results in relation to parent-reported child problem behaviours were not as clear cut, intervention parents did report a significant positive change at follow-up indicating that further investigation of this outcome is warranted.

Parents in the TPOL-D were afforded flexibility in relation to both the amount and mode of facilitator contact they experienced throughout the program. It is suggested that this flexibility encouraged parents to engage with their support in a manner that was sufficient to meet their individual needs – 'minimal sufficiency' is a concept that is not only important at a clinical level but also more broadly at a population implementation level where efficient programming is required to maximise reach and minimise cost and demand upon limited resources (Prinz & Sanders, 2007).

Finally, parents indicated that they felt they had the support of a therapist while completing TPOL-D, reporting via both qualitative report and the WAI-SR, forming a strong, positive working alliance with their remote therapist despite never having any in-person contact with this therapist at any time during the intervention. As a strong therapeutic alliance has consistently been linked with positive therapeutic outcomes (Anderson et al., 2012; Schmidt et al., 2014) this finding has promising, albeit very preliminary, implications for clinical practice.

#### Ethical implications of delivering telehealth services

With interest in and use of telehealth services on the rise for intervention delivery, consideration as to the challenges of providing competent and ethical care in this modality is

also required (Drum & Littleton, 2014; Sansom-Daly, Wakefield, McGill, Wilson & Patterson, 2016). While a number of professional organisations and expert groups have responded by producing best-practice guidelines to assist professionals to deliver online interventions in an ethical manner (American Psychological Association, 2013; Australian Psychological Society Limited, 2013) differences at a country or state level as to who can provide such services, how these services are provided, how clients are assessed as being appropriate to receive telehealth service, how data is to be kept confidential and so on are apparent. Further, therapists will also need to be mindful to evaluate their own competency to deliver interventions and services in these novel modalities (Childress, 2000). While undoubtedly the purview of future research, the implementation of telehealth programmes such as TPOL-D on a global basis will involve much more than simply keeping up with technological advances and consumer preferences, but will also involve the consideration of potentially novel legal requirements, ethical standards and professional boundaries (American Psychological Association, 2013).

### Strengths and limitations

The strengths and limitations of each study were identified and discussed at the end of the relevant chapters; therefore, these specific points will not be discussed again here.

In addition to the limitations already noted in the dissertation chapters, the generalisability of the results from both the parenting survey and RCT must be read with caution. In order to keep the parent survey brief, demographic details of respondent parents were kept to a minimum, making it impossible to draw any conclusions about respondent parents' socioeconomic and ethnic background or the nature of their child's disability. While the RCT collected a greater range of demographic information, results indicated that parents were from a relatively homogenous group in that there were only a small proportion of single parents, all parents spoke English, most were employed (and/or their partners were employed), and the vast majority of respondents were mothers.

A further limitation given the mixed-disability focus of TPOL-D was that while extensive recruitment was undertaken to target as broad a disability population as possible, parents of children with ASD formed a majority in the RCT study.

From a technological perspective, while the programme was open to all parents of children with a disability, a limiting factor was that parents were required to have access to a higher-speed internet connection to be able to view the online modules in a timely manner.

Finally, while a key advantage of telehealth-based interventions is that delivery is not hampered by distance, in terms of intervention evaluation the use of multimodal forms of evaluation is restricted. The use of parent self-report measures at all stages of the research, and the accompanying potential for social desirability or perception bias in the parent self-report data is acknowledged.

Despite the limitations described, there are several strengths of the current research that should also be acknowledged. Overall, the dissertation appears to be the first of its kind to examine a telehealth parenting intervention for parents of children with mixed disabilities. It also appears to be the first study to use direct consultation with consumer-parents to help inform the development of a novel telehealth intervention for this population with the developed intervention then being implemented and evaluated as part of the one research arc.

To assist in the fidelity of delivery, all TPOL-D parents were provided with therapist assistance by the dissertation author. This also permitted satisfaction with therapist support and therapeutic alliance formed to be assessed without the confounding effect of multiple therapists. The use of both quantitative and qualitative analyses helped to clarify nuances of parents' perceptions of and satisfaction with TPOL-D in a way that would have not been possible with standard quantitative measures of acceptability and satisfaction alone. Intervention adherence rates were high with minimal programme drop-out (10%). Finally, the RCT had sufficient power and sample sizes to produce meaningful results.

### **Future research**

Suggestions for future research have already been discussed after each study and those points will not be repeated here. This section aims to build on prior discussions.

There are several areas that may require further examination when examining the efficacy of TPOL-D. Given the relatively homogenous sample of parents recruited, the results from the parent survey and/RCT may not necessarily generalise to socio-economically and ethnically diverse families, nor does the sample size reported support generalisation of findings to specific disability populations. With one of the main goals of telehealth parenting interventions being to increase dissemination of these services, future research would benefit from evaluating TPOL-D with targeted populations of parents as well as larger sample sizes.

While parents and carers rated the components of TPOL-D in terms of perceived utility to them, it would be inappropriate to claim that any components or strategies caused programme success or that the inclusion of other components led to less optimal outcomes. Similarly, while it is the author's belief that parents in TPOL-D explored their disability-

specific needs while interacting with their remote therapist and used the online modules for general parenting skills training, the veracity of this belief is unable to be determined in the absence of further research. Returning to the theme of a 'minimally sufficient' intervention (Sanders & Prinz, 2007), future research is therefore required to determine which of the components of TPOL-D may or may not contribute to positive programme outcomes.

It would also be of benefit for further research to explore whether satisfaction with the intervention was moderated by factors such as the remote therapist, parent, family or child characteristics (e.g., type and severity of disability). Previous experience with computers has been found to influence the way people judge Internet-based contact (Mallen, Day & Green, 2003), while Carey, Wade and Wolfe (2008) found that prior technology use impacted upon treatment response, but did not impact upon therapeutic alliance and treatment satisfaction. Future research studies should consider examining parent-participant's prior exposure parenting programmes (clinic-based and telehealth), as well as degree of familiarity and/or comfort with a range of telehealth technologies. This would also allow exploration as to whether these factors moderated satisfaction outcomes.

The current research employed a very rudimentary approach to assessing the working alliance formed between TPOL-D parents and their remote therapist. Future research may consider measuring alliance at multiple time points throughout treatment, including at baseline (immediately post questionnaire completion), mid-treatment, and post-treatment to gain a greater understanding of the progression of the therapist-client interaction across time.

Finally, implementation of TPOL-D into routine clinical practice is also a key area for future exploration. The present research results indicate the efficacy of the intervention under strict research guidelines. One SSTP-accredited therapist with substantial experience working with parents of children with a disability provided all remote therapeutic contact, while also being able to offer contact at highly flexible times. The effectiveness of the intervention in real-world settings with potentially fewer resources and controls needs to be determined.

#### **Final comment**

Telehealth technologies offer hope for the widespread diffusion of evidence-based interventions by increasing accessibility and reducing costs (Jones et al, 2013). The overall aim of this thesis was to investigate the efficacy of a novel telehealth intervention for parents of children with mixed disabilities. The thesis has demonstrated the paucity of intervention research in this area, yet has also illustrated that parents of children with a disability parents are in great need of such support. Given the life-long impact that a disability may have on a

child, their family and the community, and the reciprocal relationship between child and parent functioning, providing effective and accessible interventions for parents of children with a disability is vital. While further research is required, the current dissertation is a valuable addition to a limited research field, providing preliminary support for the efficacy of TPOL-D in providing an effective, accessible and engaging telehealth intervention for parents of children with mixed disabilities.

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# Appendix A

# Telephone/email weekly guideline – Session 1



# TRIPLE P ONLINE - SESSION 1 CHECKLIST

Use this guide as record of what was covered in each session. Indicate with a tick ( ) if the item was covered. Leave blank if the item was omitted.

Parent ID:		Parent nar	ne:	
Start time:				Finish time:
Session date:			La	ast TPO module completed by parent:
Practitioner:				
Process issue				
(indicate reason Tech	on):** nical difficul <sup>:</sup> ot ousy/did not	ties get around to	o it	essed to next module since last session transfer transfer transfer transfer transfer transfer to the since last session transfer
Reason: Cand Pare Pare Too	elled at pare nt did not an nt away (e.g many resche nt cancelled	a missed sess ent's request of aswer/unable to perior of the services of the assessing the services of the ser	due to be ) s fro	m parent
issues. In the	ese situatio ules, and pro	ns, review a	ınd	with the phone consultation despite these discuss any previous goals from past entify an adherence plan (near bottom).
☐ Check tha	it parent has	s successfully	log	ged in to Triple P Online
Review m	odule progr	ess (has pare	nt c	ompleted first module?):
Ask parent to set the agenda (suggestion for Session 1: what are parent's main concerns? Main changes they want to see during the program? Any other specific issues for discussion?)				
	odule conte ent to identify		nost	important ideas from last module:
-continuental and a second and a		iciestatoro de estatoro constituido constituido de estatoro de estatoro de estatoro de estatoro de estatoro de	34040m(34144)4044	
☐ Review go	pals/practice	e tasks:		

1

	<ul> <li>Ask parent to identify their goals from last module (refer to Get Active component of module). Use minimal prompting to help parent identify or refi goals if necessary:</li> </ul>
	Review progress (how have you gone with these goals so far?) Check what has been working well:
	Ask what they could have done differently:
an	Discuss any other agenda items (use minimal prompts to help the parent solvey problems):
ac	[If necessary] Discuss adherence plan (i.e. prompt parent to plan time to cess program during coming week):
	Review and summarise session  • Prompt parent to review their goals/practice tasks for the coming week:
	Prompt parent to identify any module content they feel they need to review:
	Wrap up and confirm next appointment:
D	ate: Time: