



UNIVERSITY OF TASMANIA

Helping Children with Autism Package – Parents’ Perspectives

by

Kathleen D. Wilson, B.Ed., M.Ed.

Submitted in fulfilment of the requirements for the Degree of Master of Education

Faculty of Education

University of Tasmania

June 2013

Declaration of Originality

This thesis contains no material which has been accepted for a degree or diploma by this University or any other institution except by way of background information and duly acknowledged in the thesis, and, to the best of my knowledge and belief, it contains no material previously published or written by another person except where due acknowledgement is made in the text of the thesis.

Statement of Authority

This thesis may be made available for loan and limited copying in accordance with the *Copyright Act* 1968.

Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes of human and animal experimentation, the Guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.



Kathleen (Kate) Wilson

Contents

Abbreviations and Terms	i
List of Tables.....	ii
Abstract.....	iii
Chapter 1 – Introduction.....	1
<i>1.1 Background and Content – Australian early Intervention review and research.....</i>	<i>1</i>
<i>1.2 The Helping Children with Autism Package.....</i>	<i>3</i>
Chapter 2 – Literature Review	6
<i>2.1 Introduction.....</i>	<i>6</i>
<i>2.2 Child characteristics.....</i>	<i>7</i>
<i>2.3 Parental stress and having a child with ASD.....</i>	<i>8</i>
<i>2.4 Internal and external stress factors.....</i>	<i>9</i>
<i>2.5 Internal stressors.....</i>	<i>11</i>
<i>2.6 External stressors and coping factors.....</i>	<i>12</i>
<i>2.7 Mitigating factors.....</i>	<i>14</i>
<i>2.8 Parental gender differences with stress.....</i>	<i>15</i>
<i>2.9 Comparative studies.....</i>	<i>17</i>
<i>2.10 Age related studies.....</i>	<i>18</i>
<i>2.11 Weaknesses in previous research.....</i>	<i>19</i>
<i>2.12 The Parental Perspectives Questionnaire.....</i>	<i>20</i>
<i>Summary.....</i>	<i>21</i>
Chapter 3 – Methodology	22
<i>3.1 Participants.....</i>	<i>22</i>
<i>3.2 Instrument.....</i>	<i>23</i>
<i>3.3 Procedure.....</i>	<i>24</i>
Chapter 4 – Results	26
Part A	
<i>Demographic characteristics of the participants.....</i>	<i>26</i>

<i>Table 1</i>	27
<i>Table 2</i>	28
Part B	
<i>Participants' responses to the survey rating questions</i>	28
<i>Table 3</i>	30
<i>Table 4</i>	32
Part C	
<i>Participants' responses to the program using open questions</i>	34
<i>Table 5</i>	34
<i>Table 6</i>	35
<i>Table 7</i>	36
<i>Table 8</i>	37
Chapter 4 – Discussion..	39
5.1 <i>Current Findings</i>	39
5.2 <i>Themes Emerging</i>	39
5.2.1 <i>Theme 1: Child Variables</i>	39
5.2.2 <i>Theme 2: Parental Competency</i>	42
5.2.3 <i>Theme 3: Reduced Stress and Anxiety</i>	43
5.2.4 <i>Theme 4: Other Factors that Enhance Wellbeing</i>	45
5.3 <i>Suggestions for Future Research</i>	46
5.4 <i>Limitations and Future Research</i>	47
Chapter 6 – Conclusion.	50
References.	53
Appendices	59

Abbreviations and Terms

ASD - Autism Spectrum Disorders.

HCWA Package - Helping Children with Autism Package.

Stress - a demand on physical or mental energy.

(Australian Concise Oxford Dictionary, 2004).

Stressor - a constraining force or influence placed on the family unit that produces, or has the potential to produce, changes in the family's existing equilibrium. (Twoy et al., 2007).

Parental stress - the perception of extra tension in the family network that upsets the family balance.

Early Intervention – Developmentally appropriate programmes for young children from birth to six years.

FaHCSIA - Department of Families, Housing, Community Services and Indigenous Affairs.

DOHA - Department of Health and Ageing.

DEEWA - Department of Education, Employment and Workplace Relations.

PPQ 2011 - *Parental Perspectives Questionnaire* (Wilson & Hay, 2011).

List of Tables

Table 1: Demographic information associated with participants

Table 2: Demographic characteristics of participants

Table 3: Mean and standard deviations responses in order of importance

Table 4: Factor loading after rotation

Table 5: Average level of services accessed in the HCWA package

Table 6: Average number of other services accessed independent of HCWA

Table 7: Identified parental concerns of child with an ASD

Table 8: Open ended questions responses

Abstract

The aim of this research was to evaluate the *Helping Children with Autism* Package (HCWA) from the perspectives of a sample of participating parents with a child with Autism Spectrum Disorders (ASD). The evaluation focused on parental self-efficacy and indirectly on parental stress and the parents' reported child outcomes. To date in Australia there is little descriptive data on parents' perceptions of the HCWA package or its effectiveness to help ameliorate negative factors associated with parenting a child with ASD. The HCWA funding package is an early intervention program designed to provide support, programs, and interventions to children with Autism Spectrum Disorders ASD under the age of seven and their parents.

A 43 item questionnaire entitled *Parents Perceptions Questionnaire* (Wilson & Hay 2011) was developed to gather the data. This instrument included both open ended questions and Likert scale questions. The sample comprised 20 participants, all of whom were parents who had accessed the HCWA package.

Overall, the parents reported positive outcomes associated with their participating in programs linked to the HCWA package. In particular they reported improved educational outcomes for their child and higher levels of support and self-confidence as a parent. The parents valued the opportunity to have both choice and greater access to intervention services and reported a strong desire for the continuation of the HCWA package after their child turned seven years of age. The findings support the notion that access to early intervention programs improves the developmental outcomes for the child and compliments and supports families in their care-giving role.

Chapter 1 – Introduction

The research literature has repeatedly reported that parents raising children with ASD experience higher levels of stress than any other cohorts of parents (Roberts & Prior 2006; Mao, 2012; Schieve, Blumberg, Rice, Visser & Boyle, 2007; Wallace & Rogers 2010; Walsh, Mulder, & Tudor, 2013). This parental stress is also linked to higher levels of mental health problems fewer coping support mechanisms and greater social isolation of the parents, family and the child with ASD (Zablotsky, Bradshaw, & Stuart, 2012).

Reporting on the Australian context Prior and Roberts (2006) identified the elevated levels of stress in parents with a child with ASD reduced a parent's capacity to cope and to effectively undertake parental tasks and they argued that due consideration must be given to any intervention designed to ameliorate stress for parents of children with ASD. In response to these concerns the focus of this thesis and the research undertaken was to consider the effectiveness of parents accessing the *Helping Children with Autism* (HCWA) package in light of the research literature on parental well-being and stress in ASD.

The research sought to explore three broad questions:

- What were the perceptions of parents who accessed the HCWA Package in light of research on well-being and stress in this population?
- What were the benefits / outcomes from accessing the HCWA Package?
- What were the psychometric properties of the *Parental Perspectives Questionnaire* PPQ developed by Wilson and Hay (2011).

1.1 Background and Context - Australian early Intervention review and research

In the Australian context, parents raising children with ASD have traditionally received little additional financial support from the Commonwealth government to access intervention services. Some states provided these services as part of government provision for

young children with additional needs but little further fiscal support was given in relation to the intervention itself. Since 2008, the HCWA initiative has provided families with a financial means by which to choose and access early intervention using funds provided by the Australian government.

The incidence and prevalence of ASD remain a contentious issue due to the current lack of any clear biological marker for the condition and its increasing prevalence (Mao, 2012). In part, the impetus for the HCWA Package came from the perception that potentially, the incidence of ASD was increasing (Prior & Roberts, 2006). In response to this, the Australian government via Department of Health and Aging (DoHA) commissioned the publication *A Review of Research to identify the most effective models of practice in Early Intervention for Children with Autism Spectrum Disorders* (Roberts & Prior, 2006). This paper analysed the various forms of intervention cited for young children with ASD and examined the research evidence pertaining to the effectiveness of each of the types of interventions identified. The notion of effectiveness was explored in relation to findings based solely on children's developmental outcomes, and the authors acknowledged that findings were not presented in relation to the associated costs or benefits for families, parents or society at large.

In a follow up study by Prior, Roberts, Rodger, Williams, and Sutherland (2011) on the HCWA program it was recommended that greater monitor of the effectiveness of the HCWA program needed to occur. Prior et al. (2011) also recommended for greater accountability of the HCWA funding through on-site visits, questionnaires and/or parents surveys, particularly for parents of children with ASD from regional and rural locations.

Thus, the research by Roberts and Prior (2006) and Prior et al. (2011) have acted as a catalyst for further deliberations in relation to Early Intervention in ASD. The current study is thus based on the theory that early intensive intervention provides families and children with ASD with the positive outcomes but there is need for greater evidence to support this theory (Wallace & Rogers, 2010). It also responds to concerns raised by Australian parents of children diagnosed with autistic spectrum disorder for the need to provide more educationally related support to children with ASD (Bryer, Grimbeek, Beamish, & Stanley, 2004; Foreman, & Arthur-Kelly, 2008; Winn & Hay 2005) and that this support needs to start early (Beamish, 2008; Paynter, Scott, Beamish, Duhig, & Heussler, 2012; Matson, Wilkins, & González, 2008).

1.2 The *Helping Children with Autism Package*

The HCWA package was an Australian Government initiative instigated in 2008 to provide financial assistance for parents with young children with ASD in the birth to 7 years age group. The package purpose falls into two categories, namely to increase access to Early Intervention services for children and secondly to provide education and support for parents and families who have young children with ASD.

The HCWA Package has been delivered jointly through the Department of Education, Employment and Workplace Relations (DEEWR), the Department of Health and Ageing (DoHA), the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and Autism Associations through the Autism Advisor Service across Australia. (HCWA Autism Advisors Operational Guidelines 1 July 2011).

As identified in the HCWA Autism Advisors Operational Guidelines (2011) the package is Australia wide and includes:

- An Autism Advisors Service to assist families and carers of children aged up to six years diagnosed with an ASD;
- Funding to increase access to Early Intervention services for children aged up to six years diagnosed with an ASD;
- Play-Connect Playgroups for children aged up to six years diagnosed with an ASD or ASD like symptoms, and their siblings;
- Early Days Workshops that deliver flexible and targeted support for families and carers of children with an ASD or ASD-like symptoms;
- The Raising Children Network's dedicated component for autism specific information, online resources and workshops, and other interactive functions for parents, carers and professionals;
- Positive Partnerships, which provides professional development for teachers and other school staff to support school students with an ASD to achieve better educational outcomes; and workshops and information sessions including access to online workshops and information is available to parents and carers of school aged children with an ASD; and
- Medicare rebates (Government financial support for health care) for diagnosis and 20 visits for Early Intervention treatment for children with ASD.

The HCWA Package had been established to augment or complement current services and it is not intended to replace state or territory government responsibility for the provision of Early Intervention service to young children with ASD and their families. The aim of this

research is thus to examine parents' perceptions of the Package in light of the research literature on parental well-being and stress using a specifically designed instrument.

Chapter 2 - Literature Review

2.1 Introduction

The focus of this thesis is to consider the perspectives of parents accessing the Helping Children with Autism (HCWA) package in the context of the research on parental well-being and stress in ASD. The HCWA package is an Australian Government initiative established to provide increased access to early intervention services for children aged birth to 7 years with ASD. The funding provides an opportunity for children with ASD, to access multidisciplinary, evidence based early intervention in order to facilitate their improved cognitive, social and behavioural outcomes and in so doing provide support for their parents. There is ongoing support for such early intervention which have demonstrated improvements to the on-going cognitive development of the child with ASD (Dawson, 2008; Sallows & Graupner, 2005). Australian families (and so Tasmanian families) have had access to this funding since 2008. One of the assumptions in providing this type of support to children with ASD is the expectation that the children's parents will benefit by increasing their understanding of ASD and how it manifests in their child and thereby reducing their anxiety and stress (Gray, 2006) and develop and enhance their resilience to the difficulties associated with having a child with ASD (Bayat & Schuntermann, 2013). Before considering parental wellbeing and stress associated with parenting children with ASD it is important to identify the condition and provide a context for understanding the parents' needs.

2.2 Child characteristics

Child behavioural characteristics and the level of severity of the ASD play a major role in the intensity, frequency and duration of parental stress and parents need for support (Benson & Dewey 2008; Lecavalier, 2006; Plant, 2007; Sheive, Blumberg, Rice, Visser, & Boyle 2007; Walsh Mulder & Tudor, 2013; Tomanik, Harris & Hawkins 2004). Bitsika & Sharpley. (2004) found that over 90% of the 107 parents involved in an Australian study commented that they were sometimes unable to deal with their children's behavioural difficulties and were consequently stretched beyond their abilities, feeling angry and frustrated, inadequate, depressed, and isolated and lonely. Unlike the parents of typically developing children, parents of children with ASD report more "fears" that their child may not fully develop the required set of adult independent living skills (Kersh, Hedvat, Hauser-Cram, 2006; Sharpley, Bitsika & Efremidis, 1997) and so be dependent on their parents. These concerns about independence can put strains on family relationships and level of family functioning (Mao, 2012) as well as increase levels of parental depression, and decrease levels of parental mental health (Baker, Blacher & Olsson 2005; Herring, Taffe, Tonge, Sweeney & Einfeld 2006).

There is broad agreement regarding the notion that a child's levels of severity of ASD influenced parental stress, the literature also puts forward differing views as to the origin of this parental stress and these are identified below:

- impairments in family and other social relations (Dunn, Burbine, Bowers & Tantleff-Dun 2001; Walsh, Burbine, Bowers, & Tantleff-Dunn 2013);
- the permanency of the child's condition (Wallace & Rogers, 2010; Sharpley et al., 1997);

- child's cognitive functioning (Baker, McIntyre, Blacher, Edelbrock & Low 2003; Matson, & Smith, 2008);
- child's level of lack independence (Bitsika et al., 2004);
- the diagnosis and severity of ASD (Davis, 2008; Mak, Ho, & Law, 2007);
- the time and age of the diagnosis (Mao, 2012; Sharpley et al., 1997);
- time since diagnosis (Benson et al., 2008); and
- behaviour issues (Baker et al., 2003; Hastings & Brown, 2002; Herring et al., 2006; Lecavalier, Leone & Wiltz 2006; Tomanik, Harris & Hawkins 2004).

2.3 Parental stress and having a child with ASD

The claim is that parents who have a child diagnosed with ASD have both increased their level of stress and need for support (Cappe et al., 2011; Davis & Carter, 2008, O'Brien, 2007). In particular, O'Brien stated that for parents:

An autism diagnosis is not a time constrained situation but one in which parents must live with the contradiction inherent in recognizing the irreversible nature of the child's condition while maintaining a long-term commitment to the child's upbringing (O'Brien, 2007, p.144).

In addition, the claim is that the coping strategies within the family unit are also severely taxed in response to the complex nature of the ASD condition (Benson, 2006; Benson & Dewy, 2008; Zablotzky et al., 2012). For example, Gray (2006) posited that as a challenge to the family structure and functioning, autism ranks among the most stressful of childhood developmental disabilities. Having a child with autism often requires parents and other members of the family to deal with issues of communication difficulties, heightened levels of emotional expression and antisocial behaviour on the part of the child with ASD

(Benson, 2006; Benson et al 2008; Davis et al 2008; Higgins, 2005). For some families, these demands can be frequent, of a high intensity and long duration, requiring the caregivers of the child to be constantly dealing with the stress of managing the child's behaviour (Bitsika et al 2004; Walsh et al 2013). Furthermore, Bitsika and Sharpley reported that this stress also impacted upon the relationships between family members and the parents' ability to relate to others, and as such they need ongoing support.

Having to cope daily with the physical and emotional demands of parenting a child with ASD may pose a threat to parents' psychosocial well-being. Further claims are made that parent's self-confidence and self esteem can be eroded in the face of the totally unfamiliar child behaviour and ongoing demands (Gray & Holden, 1992; Holroyd & McArthur, 1976; Winn & Hay, 2005). In addition, it has been reported (Davis & Carter, 2008) that caregivers of a child with ASD often experience helplessness, feelings of inadequacy and failure, shock, guilt, frustration, and resentment.

Given that coping, stress and support are connected, considerations of the operational definitions are warranted. Stress is defined as a demand on physical or mental energy (Australian Concise Oxford Dictionary, 2004). For the purpose of this research, a stressor is a constraining force or influence placed on the family unit that produces, or has the potential to produce, changes in the family's existing equilibrium (Twy, Connelly & Novak 2007) and parental stress refers to the perception of extra tension in the family network that upsets the family balance. This latter definition provides some insight into the significance of intervention like the HCWA package, when raising a child with ASD, as the intervention itself may address family balance by potentially reducing parental stress and thereby enhancing their ability to cope.

2.4 Internal and external stress factors

Twoy et al. (2007) have reported that unlike other “illnesses” or events, having a child with Autism is not short lived but rather it is a lifetime of multidimensional issues that place ongoing and changing demands on the family. Efforts to comprehend the extent of this impact have often focussed on two main areas: (i) the degree of severity of the ASD and the type and level of challenging behavior (Benson, 2006; Hay & Winn, 2012); and (ii) the level and type of social support available to the family (Cappe, Wolff, Bobet, & Adrien, 2011; Winn & Hay, 2005).

Useful comments have been made regarding these two factors in relation to internal and external sources of stress; for example, Twoy et al. (2007) maintained that for a family with a child with ASD the internal stressors come from within the family and the external stressors are those pertaining to advocating for health, social and educational services for the child. Sharpley et al (1997) reported that the three most stressful factors arising from parenting a child with ASD were: (1) the permanency of the condition; (2) the lack of acceptance of Autistic behaviours by society and family members; and (3) the low levels of support provided by health care services and other social services. This last factor is of particular interest as it suggests that the HCWA package may alleviate some of the parental external stressors related to accessing appropriate evidence based early intervention services for their children.

Sharpley et al. (1997) are not the only researchers suggesting that direct and indirect services to the child with ASD can benefit the child and the family with Tunali and Power

(2002) and Mao (2012) making a similar suggestion. Tunali and Power maintained that families of children with developmental disabilities need support because they experience chronic stress and that the hardships on family life fall into eight broad categories: (1) financial hardships; (2) strained emotional relations within the family (e.g., overprotection, conflict); (3) modifications in family activities and goals (e.g., less time for leisure, modification of career goals); (4) impact on social life (e.g., isolation, perceived social rejection); (5) complexity and time burdens of medical treatment; (6) housing adaptations; (7) educational hardships; and (8) parental grieving. The research findings of Bitsika et al. (2004), Twoy et al. (2007) and Mao (2012) attest to the claim that parents with a child with ASD need direct and indirect support.

2.5 Internal stressors

Parental stress and parents use of coping strategies is a multidimensional issue but having a child with ASD typically has a negative psychological impact on the parents. The psychological domains that are impacted include:

- poorer coping strategies (Gray, 2006; Higgins, Bailey, & Pearce (2005); Hall & Graff, 2011; 2005; Sivberg, 2002; Smith et al., 2008);
- higher levels of anxiety and depression (Bitsika et al., 2004; Baker et al., 2003; Davis et al 2008; Weiss, Cappadocia, MacMullin, Viecili, & Lunskey, 2012);
- lower locus of control (Dunn, 2001; Sharpley & Bitsika, 1997);
reduced self-efficacy (Hastings, 2002);
- less cognitive self-appraisal (Plant et al., 2007);
- greater social isolation (Hall & Graff,. 2011; Zablotzky et al., 2012)

- less optimism and more pessimism for the future (Baker et al., 2003)
- reduced sense of family coherence (Oelfsen et al., 2006; Mak et al., 2007); and
- feelings of ambiguous loss (O'Brien, 2007).

Benson and Dewy (2008) maintained that while a substantial proportion of parents with children with ASD experience levels of stress associated with child-related characteristics, higher levels of stress were also associated with parents' perceptions of their own care-giving abilities. Bitsika and Sharpley (2004) and Mao (2012) found that clinically significant levels of depression were associated with the parents' perceptions of the expertise of the family caregiver, with both anxiety and depression being higher in parents who held a poorer opinion of their caregivers' expertise.

2.6 External stressors and coping factors

Although an examination of stress and well-being in parents of children with ASD has been well documented in the research literature, less attention has been given to external or environmental sources of stress. Sharpley et al. (1997) defined "social support in terms of the presence/absence of a clear understanding of the child's disorder by those immediate family members who provided respite from the day-to-day demands of parenting" (p.21). In addition, Hill (2007) maintained that social factors strongly influence parental stress and well-being levels and these social factors included an insufficient level of understanding about the condition, a lack of supportive and positive social support and the reported quality of support from immediate partners and other social relationships.

In particular, Cappe et al. (2011) argued that based on quality of life variables, parents of children with ASD needed additional support and they argued for the development of relevant support and assistance programs specifically designed for this cohort. These are not the only researchers make this claim about the quality of life and parenting children with ASD. The following external parental stressors have been identified and all associated with poorer quality of life outcomes for parents of children with ASD:

- insufficient access to a number of crucial commodities including: social support (Dunn, 2001; Sharpley et al., 1997);
- reduced finances and career opportunities for care givers (Benson et al., 2008; Gray, 2003);
- poor care provided to siblings of children with ASD (Bitsika & Sharpley, 2004; Rivers & Stoneman, 2003);
- lower levels of partner support and marital relationships (Baker, 2005; Plant, 2007; Sharpley et al., 1997; Kersh, 2006; Rivers & Stoneman, 2003);
- limited availability of respite care (Bitsika & Sharpley, 2004);
- low levels of understanding of the child's ASD by immediate and other family members (Sharpley et al., 1997);
- lack of acceptance of child's autistic behaviour by society and social support network (Zablotsky et al., 2012);
- lack of counselling and stress management services (Bitsika & Sharpley, 2004; Wallace & Rogers, 2010) and
- greater scarcity of general resources (Twyo et al., 2007).

Twyo et al. (2007) argued that even when services are available the lack of co-ordination between services means that parents with a child with ASD have to cope with

multiple agents and different individuals often providing an ad hoc service that placed demands on the parents in terms of their time and time management skills, their ability to transport their child to the services and meet these increased costs, and follow through and implement the education and therapy activities often only initially demonstrated by others. Given these concerns, how a service is delivered is important and poorly delivered or inappropriate services can compound the levels of stress on the parents of children with ASD.

2.7 Mitigating factors

Parents' cope in a variety of ways with having a child with a disability and the evidence is that social support can act as a buffer against some of their environmental stressors (Dunn et al., 2001; Rivers & Stoneman, 2003). The problem is that parents who have a child with a disability may withdraw from support, social relationships and recreational activities, the very activities that may well serve to act as a barrier against the stress associated with caring for a child with ASD. This withdrawal may be in response to the sense of helplessness that often accompanies a lack of understanding of the nature of their child's disability or a fear that they will have negative scrutiny from within the family or by the broader community or the service providers (Dunn & Gray, 2003; Weiss et al., 2012).

This sense of helplessness may reduce parents' desire and enthusiasm to access the very support that could enhance their well-being and mitigate their stress. Building coping and resilience within parents is thus an important strategy in early intervention programs for children with ASD and their families (Bayat & Schuntermann, 2013). On this point Wallace and Rogers (2010) have argued that support to the children with ASD and their parents need

to start early and the critical time period for children with significant problems is often less than three years of age.

Some attention to the degree of external support that mitigates stress has been given with Benson et al. (2008) conducting a study of 55 parents of children with ASD to determine and rank the resources parents' believed were most important in reducing their stress levels. Parents ranked highly the need for financial assistance, support for family members, and for professional support. There were some reported differences regarding the gender of parents in that fathers rated, among other things, support of spouse highest, whereas mothers rated monetary support as their highest need. (Benson et al., 2008). This finding has implications for further research into the impact of program differences in association with service provision.

2.8 Parental gender differences with stress

Studies on the internal stressors of parents of children with ASD have also focused on gender differences in association with stress and coping (Benson, 2008; Dunn, 2001; Gray, 2003; Hastings, 2003; Kersh et al., 2006; Sharpley et al., 1997). The general trend is that compared to fathers, mothers have higher levels of stress and more problems coping in general with the child (Hastings, 2003). In particular, research outcomes support the notion that mothers usually score higher on measures identifying levels of anxiety and depression (Sharpley et al., 1997) and weaker on measures determining a sense of coherence (Oelofsen et al., 2006) and locus of control (Dunn, 2001; Wallace, & Rogers, 2010). These studies also include maternal and paternal differences in care giving abilities (Benson, 2008) and level of optimism and pessimism (Baker et al., 2005). Dunn (2001) compared maternal levels of

stress between mothers of children with ASD and mothers of children with Down Syndrome and reported that mothers of children with ASD reported less parenting competence, less marital satisfaction, and less adaptability than mothers of children with Down Syndrome or mothers of typically developing children.

Mothers of children with ASD have been identified as being more anxious, more depressed, and reported being stretched beyond their limits more times per month than fathers (Bitsika et al., 2004). Mothers are no doubt more exposed to the constancy of stressful events, according to Gray (2003) and use different coping and adaptive strategies. Therefore, it is possible that these stressful life events lead to higher psychological stress and depression in mothers than in fathers who have a child with ASD.

Other research cites that differences in parental stress in ASD are most often expressed as:

- differences perceived in marital quality, (Kersh et al., 2006) and function (Tunali et al., 2002);
- child behaviour and the incidence of depression in the partner, (Hastings et al., 2005; Weiss et al., 2012)
- partners' mental health, (Hastings, 2003; Davis et al., 2008); and
- increased anxiety and depressive symptoms, (Dunn, 2001; Sharpley et al., 1997; Oelofsen & Richardson 2006; Bitsika et al., 2004; Tzoy et al., 2007).

In addition, it is claimed that mothers respond to stress associated with having a child with ASD by redefining their expectations and developing routines that put more structure and organization into their lives (Hill, 2007; Tunali et al., 2002). Fathers' coping strategies

are less well researched and fathers are generally under-represented in the research literature on parental stress and coping with having a child with ASD (Gray, 2003). This may be, in part, due to the traditional roles that fathers play in maintaining paid employment and being less involved in care giving roles, and having less responsibility for home duties (Kersh et al., 2006).

Kersh et al. (2006) also maintained that the differences between maternal and paternal coping have been attributed to the notion that for mothers, marital quality was a predictor of parenting self-efficacy, but that for fathers their self-efficacy was derived more from factors outside the home and was more centered on work. Gray (2003) argued that the most striking difference between the mothers and fathers in his study was the differing personal impact of their child's ASD. Although most fathers noted the severe difficulties that their child's ASD presented for their families, they usually claimed that their child's condition did not have a significant impact on them personally, a perception that was in stark contrast to that of the mothers. These findings support the notion that while mothers are more likely to facilitate their child's access to intervention programs, both parents, including the needs of fathers should be given due consideration.

2.9 Comparative studies

The evidence suggests that parents of children with ASD develop a range of coping strategies (Bayat & Schuntermann, 2013) but even so they still have a higher level of stress when comparative research studies with parents who do not have a child with ASD have been conducted (Cappe et al., 2011; Hall & Graff, 2011). In terms of coping levels, Pisula (2007) researched the stress profiles of mothers of children with ASD and mothers of children with Down Syndrome and found that mothers of children with ASD experienced a higher level of

stress due to the unpredictability of their child's behaviour, limitations with communication with their child and the significant impact that had on care-giving tasks.

Tunali et al. (2002) compared mothers of children with ASD to mothers of children without ASD and found that mothers of children with ASD placed less emphasis on career success and were more likely to believe that mothers of young children should not work outside the home. In addition, these mothers spent more leisure time with the extended family; placed less emphasis on other's opinions of their child's behaviour; placed more emphasis on spousal support and parental roles in discussions of marriage; had more difficulty understanding their child's behaviour; and showed a marginally significant difference in their tolerance of ambiguity about their child's development (Tunali et al., 2002). In a similar research design, Sivberg (2002) compared the coping behaviours of parents with children with ASD and parents who had non-autistic children and identified that parents of a child with ASD developed the coping mechanisms of distancing themselves from the problem and/or escaping from the concern by ignoring it or passing it on to someone else.

2.10 Age related studies

There is also evidence that there is an age factor with Smith et al. (2007) investigating the well-being and coping between mothers of toddlers with ASD and mothers of adolescents with ASD. These researchers ascertained that coping strategies operated differently with regards to stress at different points in the care-giving life course. Mothers of toddlers with an ASD had lower levels of emotion-focused coping and higher levels of problem-focused coping which was associated with better maternal well-being whilst mothers of adolescents with ASD reported higher levels of anger and behavioural disengagement which may be a

reflection of the longevity of the task and the toll it has taken on parental well-being.

Comparative studies provide evidence in support of the notion that parents of individuals with ASD fare poorly in comparison to parents of children with other disabilities, more research is required to determine why this is the case and how the current trend can be altered.

2.11 Weaknesses in some of the previous research

Much of the research literature as outlined supports the notion that parents of children with ASD are more stressed than other parents and they are at risk of becoming more socially isolated and developing psychological and emotional problems and need to access more support services (Bayat & Schuntermann, 2013; Tunali et al., 2002; Weiss et al., 2012). Although, the literature is supportive of this viewpoint, there are still deficits associated in this research literature. Examples of these deficits include: an under representation of fathers with more research needed particularly in recognising the differences in stressors and the differences in coping styles from mothers; given current demographics, there is little research on single parent families and the implications of this on sole parents; there are few studies on parental stress in ASD and the associated impact on siblings of individuals with ASD, examining issues such as parental pressure applied to non ASD children in an attempt to provide some degree of normality to their lives by increasing the pressure on the siblings to perform better academically, in the sporting arena and in social pursuits; limited research data on pre and post measures of parental stress in ASD before and after intervention or access to support; few studies considering parental stress over time, and at different development stages and within different levels of severity of ASD, examining changes in coping and a rationale for why this has happened.

In addition, Prior et al. (2011) writing about the HCWA package have recommended that greater monitor of the effectiveness of the HCWA program is needed. They also called for greater accountability of the HCWA funding through on-site visits, questionnaires and/or parents surveys, particularly for parents of children with ASD from regional and rural locations in Australia. These recommendations provided a strong rationale for conducting the research planned in this study. However, to do these evaluations there is a need to design relevant parent surveys based on the relevant research literature.

2.12 The *Parental Perspectives Questionnaire* (Wilson & Hay 2011)

Given the plethora of research literature on elevated levels of stress and reduced sense of well-being in parents of children with ASD, and recognising particular deficits in the research literature, this study is in part an attempt to address the need for studies measuring parental well-being post intervention. Due to a lack of pre-existing instruments with the unique specificity required to encapsulate the data, the *Parental Perspectives Questionnaire* (PPQ) was designed. This instrument was also developed to accurately measure the experiences and perceptions of a cohort of parents accessing the HCWA package, as well as being aware of previous research data on levels of parental stress and reduced well-being in ASD. This questionnaire was designed to use both qualitative and quantitative measures and includes likert items and open ended questions. The questions in the instrument were based on the research literature reviewed and cited in this chapter, but what became clear from the review was there were no measures capturing the complex issues of coping and stress and linking such psycho-emotional dimensions to an evaluation of a specific program such as the HCWA. Hence, an outcome of the research is to evaluate the PPQ as an instrument and in

particular to identify the core parental factors it identifies with the evaluation of the HCWA program. Thus one of the research questions under investigation is: What are the psychometric properties of the *Parental Perspectives Questionnaire* (Wilson & Hay, 2011) which was developed for this study?

Summary

This chapter reviewed the research literature on parental well-being for parents who have a child with ASD and generally confirmed that these parents were an “at risk” cohort who achieved at a suboptimal levels on wellbeing and family functioning measures. Notwithstanding this, the chapter has identified that these parents do develop coping and resilience strategies but the evidence is that such strategies are best developed around programs that are designed for their needs. Therefore, the introduction of the HCWA package provided researchers with a unique opportunity to undertake evaluative research into the effects of specifically designed services for children with ASD and their parents.

Chapter 3 - Methodology

Given it is more than seven years since the Prior and Roberts (2006) report was written and three years since the implementation of the HCWA package in Australia, there is a research imperative to respond to the seemingly complex yet intransient questions cited in the work of Prior and Roberts (2006). In particular there is a need is to undertake research with families who have accessed the HCWA package from a parents' perspective (Prior & Roberts, 2006).

Therefore, the purpose of this research was to gain an insight into the perceptions of parents of children with ASD and their perspectives of services accessed from the HCWA Package and to investigate if these services helped parents cope with having a child with ASD and increase their sense of well-being. This study did not seek to determine the causality of their level of stress but rather the focus was on exploring and documenting participants' perceptions of HCWA related services and its association with parental stress. This research investigated the following questions:

- Who are the parents (the participants) who accessed the HCWA services?
- What are their perceptions of the HCWA services?
- What are the psychometric properties of the *Parental Perspectives Questionnaire* (Wilson & Hay 2011) which was developed for this study?

3.1 Participants

Eligibility to access to access the HCWA package was determined by the HCWA criteria (from HCWA Autism Advisors Operational Guidelines 1 July 2011). From this cohort of parents, parents were invited to participate in the study if they had been involved with the HCWA program for at least 12 months. If they self-selected they were provided

with a copy of the introduction letter and a copy of the *Parental Perspectives Questionnaire* (Wilson & Hay 2011) to be completed. Nineteen participants self-selected to be involved with this study. Information on the participants is included in the results chapter.

3.2 Instrument

The study used a single method approach involving a survey instrument that ascertained both qualitative and quantitative data from participants. This questionnaire was designed to enable participants to share their perceptions of the HCWA package based on their experiences. The *Parental Perspectives Questionnaire* (Wilson & Hay 2011) was developed because no other instrument was currently available which would accurately encapsulate the information required for this research. The questionnaire comprised of demographic information, parent reports on ASD severity rating, service access information and identification of parents' main concern/s about their child with an ASD. These questions were based on issues and themes identified in the parental stress literature as reported in Chapter 2 of this thesis.

The questionnaire was comprised of 43 questions; five open-ended questions (such as "what did you like least about the HCWA package?") and 38 Likert scale questions. Participants rated how accurate typical statements were (for example "I now have a better understanding of my child after accessing the HCWA package") for them on a five-point Likert scale ranging from 'Strongly disagree' to 'Strongly agree'. The psychometric properties of the *Parental Perspectives Questionnaire* (Wilson & Hay 2011) are included in the results chapter.

3.3 Procedure

After the *Parental Perspectives Questionnaire* (Wilson & Hay 2011) was initially designed the instrument was individually piloted to a cohort of 5 parents who had used the HCWA services. This pilot was intended to identify terms, vocabulary or style issues that made the comprehension of the instrument difficult. Based on this feedback minor modifications occurred to the instrument.

The Chief Executive Officer of Autism Tasmania gave permission for the researcher to liaise with the Autism Advisors to conduct this research and approach parents who have accessed the Tasmania HCWA funds. The Chief Executive Officer of Autism Tasmania was provided with a letter of introduction and information about the study and a copy of the *Parental Perspectives Questionnaire*. These items are located in the Appendix of this thesis.

To assist in gaining a cross section of participants across the state of Tasmania, 35 introduction and information letters and surveys along with self-addressed envelopes were given to the State wide Autism Advisors for distribution. These advisors either contacted, met with, or sent the information letters and a copy of the survey to some 35 parents, 19 parents of children with ASD who had accessed the HCWA services responded. In some cases where the Autism Advisors were conducting meetings they handed out the surveys to participants at the end of the meeting and the sealed envelopes were then handed back to the advisors who then passed these onto the researcher. The indications were that the participants completed the *Parental Perspectives Questionnaire* instrument in approximately 30 minutes.

Once the surveys were returned to the researcher the quantitative data was recorded onto an Excel spread sheet and then transferred to the Statistical Package for the Social Sciences 19 (SPSS 19) for analysis.

The participants' open ended questions were individually analysed for content theme responses by question, with the frequency of common responses for each of the questions tabulated.

Chapter 4 – Results

This chapter outlines the results obtained from the *Parental Perspectives Questionnaire*. The quantitative items were statistically analysed using the computer program, the Statistical Package for the Social Sciences (SPSS, 2009). The qualitative data were reviewed and organised using the frequency of common themes in the text data. The results are reported in three sections: Part A the demographic characteristics of the participants; Part B the participants' responses to the survey rating questions; and Part C the participants' responses to the program using more open questions.

Part A

Demographic characteristics of the participants

Responses from parents participating in the HCWA package were collected through Autism Tasmania, Autism Advisors from the current cohort of 19 parents accessing the program from across the state and collated in Table 1. The sample consisted of 2 fathers (age $M = 44.3$ years) and 17 female respondents (age $M = 38.4$ years). This sample of families participating in the HCWA package had, on average, 2.1 children per household with 47.3% of participants indicating university as their educational level.

The data showed that of the 19 children with ASD accessing the HCWA package, their ages varied (children's $M = 7.5$ years) as did their total time involved with the programs in package (time in program $M = 1.8$ years). The level of severity of ASD was self-reported by parents with 6 children (31.5%) having Severe ASD; 8 children (42.1%) purportedly having Pervasive Developmental Disorder Not Otherwise Specified; and 5 children (26.3%) with Asperger's Syndrome.

Table 1

Demographic Information Associated with the Participants

Age	Sex	No. of Children	Occupation	Respondent Education level	Child's age	Accessed HCWA years	ASD severity rating
42	F	2	Admin	Year 10	8	2	PDD
36	F	2	Teacher	University	6	1	PDD
30	F	1	Assistant	University	7.7	2	Severe
43	F	4	Nurse	Year 12	8	2	Severe
41	F	3	Admin	TAFE	6	2	PDD
44	F	2	Admin	University	6	1.5	AS
38	F	2	Project Officer	University	7	2	AS
40	F	2	Training Officer	University	8	2	PDD
30	F	1	Finance Officer	Year 12	6	2	PDD
50	F	1	Home duties	University	6.5	1	AS
42	F	3	Home duties	University	9	1.5	Severe
31	F	1	Admin	TAFE	7	2	AS
42	F	3	Teacher's Aide	Year 12	7.5	2	PDD
46	M	2	IT Manager	University	4	2	Severe
36	F	2	Home duties	Grade 10	6	2	Severe
42	M	3	Engineer	University	8	2	PDD
44	F	4	Home duties	Grade 10	7	2	Severe
31	F	1	Home duties	Grade 10	6	1	AS
34	F	1	Home duties	Year 12	4	2	PDD

Note. F- Female; M- Male; PDD – Pervasive Developmental Disorder Not Otherwise Specified; AS – Asperger Syndrome; Severe – severe Autism Spectrum Disorder

The majority of respondents were females with university level education and an average age of 39 years as shown in Table 2. Children were most commonly rated by their parents as having a moderate level of severity of ASD and had not completed their funding allocation of two years access to the HCWA package.

Table 2

Demographic Characteristics of Participants N =19

Variable	Frequency and average
Age	39.05 years
Sex (% female)	89.47%
Number of children	2.1
Education level	
University	47.37%
TAFE	10.53%
Year 12	21.05%
Year 10	21.05%
Child's age	6.7 years
Number of years accessing HCWA	1.79 years
ASD severity rating	2.05

Part B

Participants' responses to the survey rating questions

Statistical analysis of the parents' responses to the questionnaire items showed the highest mean response was received for question 37: "My child with ASD benefited from the HCWA package" ($M = 4.00$, $SD = 1.20$) and question 32: "I would recommend the services I received to others" ($M = 4.00$, $SD = 1.22$). The lowest mean response was received for

question 12: “The HCWA package has enabled me to spend more time focusing on my other child / children” ($M = 1.78$, $SD = 1.58$) and question 11: “Since accessing the HCWA package I spend less time focusing on my child’s future” ($M = 2.42$, $SD = 1.38$). As reported in Table 3 the data confirmed that parental perceptions of the *HCWA package* were positive, with a generally narrow range of opinions across the sample group, as demonstrated by low standard deviation scores per item.

Table 3

In Order of Importance, Mean and Standard Deviations for Parental Responses

Question	Mean	SD
My child with ASD has benefitted from the HCWA package.	4.00	1.20
I would recommend the services I received to others.	4.00	1.22
The HCWA package helps /helped my child communicate better.	3.94	1.31
The people providing the services communicated well with my child	3.84	1.30
The package made a difference to my child with an ASD and my family.	3.84	1.34
I have benefitted for the HCWA package	3.78	1.35
The HCWA package has increased my understanding of my child's ASD.	3.78	1.39
I use ideas and strategies from the HCWA package.	3.78	1.22
The package has given me information and ideas on how to help my child.	3.78	1.39
The HCWA package helps / helped prepare my child for school.	3.74	1.52
I am already aware of how to help my child.	3.73	1.36
The HCWA package is for children's learning.	3.68	1.29
The package enabled me to understand my child's behaviour better.	3.68	1.33
The HCWA package has confirmed for me that I am a good parent.	3.63	1.46
The HCWA package helps /helped my child communicate better.	3.63	1.49
The services provided were appropriate for my child.	3.57	1.38
The people providing the services communicated well with me.	3.57	1.34
I had time to talk with the service providers.	3.47	1.07
The HCWA package is aimed at assisting families (parents and children).	3.42	1.64
I now have a better understanding of my child after accessing the package.	3.36	0.34
The HCWA package services were easy to access.	3.36	1.25
The HCWA package gives parents time to focus on their child.	3.36	1.53
The services were locally available.	3.31	1.52
I feel less anxious about my child after accessing the HCWA package.	3.31	1.52
I was able to follow up on the services in the home.	3.26	1.48
The package helps my child mix with other children of a similar age.	3.21	1.47
Others in the family/home have benefitted from the HCWA package	3.21	1.51
The HCWA package offers me something as well as my child.	3.21	1.54
I now have a better sense of well-being.	3.15	1.21
Prior to being involved in the package I had a good sense of well-being.	3.15	1.11
The HCWA package helps / helped my child become more independent.	3.10	1.44
I received value for money from the services provided.	3.05	1.26
I am more confident in taking my child outside the family home and undertaking recreational activities with him / her.	3.05	1.50
All elements of the HCWA package helped my child.	3.05	1.64
The HCWA package has increased the level of harmony in the home	3.00	1.49
The HCWA package helps/helped me become a better parent for my child.	3.00	1.66
Since accessing the package I spend less time focusing on my child's future.	2.42	1.38
The package has enabled me to spend more time focusing on my other child / children	1.78	1.58

Note. M – Mean; SD – standard deviation

Main factors associated with parental responses

To identify the main parental perceptions associated with the HCWA package the parents' responses to the survey were analysed for main factors using Principal Component Analysis as the extraction method and Varimax with Kaiser Normalization as the rotation method. The obtained scree plot supported a three-factor solution.

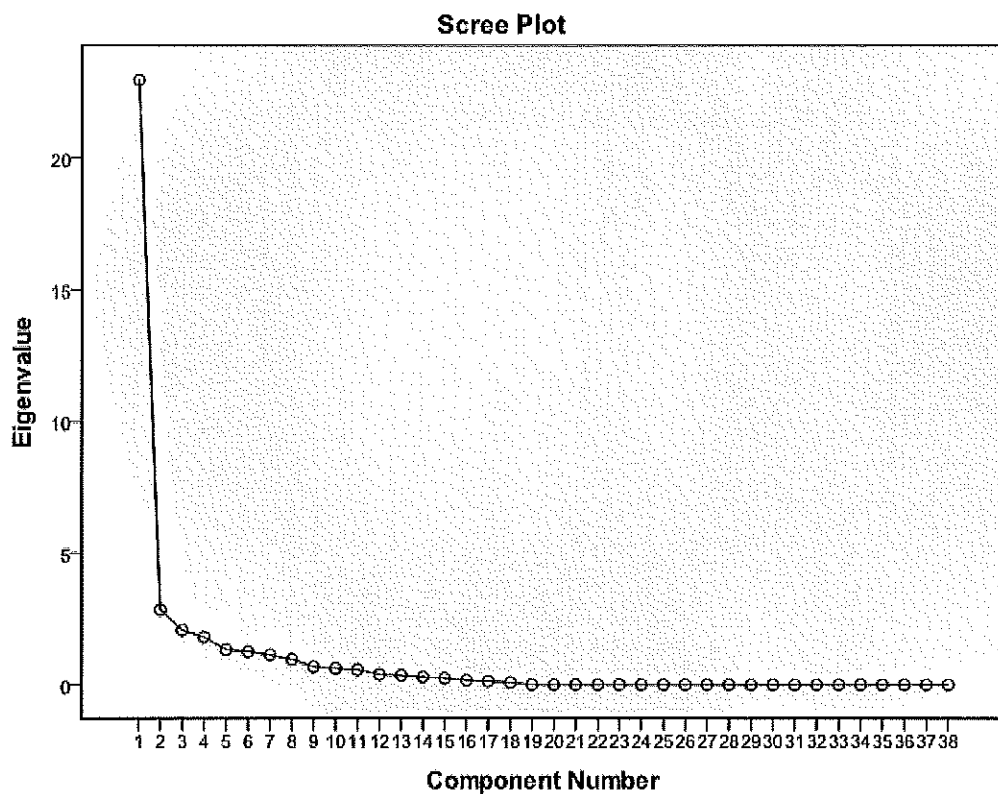


Figure 1 Scree plot for parental survey questionnaire

The three factors (Table 4) were labeled based on the loading pattern of the items to these factors, and the three factors were: The HCWA package:

- Factor 1 Benefitted my child
- Factor 2 Enhanced parent competency and self-efficacy
- Factor 3 Reduced parental stress and anxiety.

The items that load on each factor are reported in Table 4.

Table 4

Three Main Factors Associated with the HCWA Package and Item Loading

Question items	Factors		
	1	2	3
The HCWA package helps/helped prepare my child for school	.82	.33	
The HCWA package helps my child mix with other children of a similar age	.74		
The HCWA package helps/helped my child to communicate better	.58	.54	
The HCWA package gives parents time to focus on their child.	.42	.72	
The HCWA package helps/helped me become a better parent for my child	.63	.54	
The HCWA package helps / helped my child become more independent.	.49	.68	
I am already aware of how to help my child.		.50	
The HCWA package has given me information and ideas on how to help my child.		.79	
Prior to being involved in the HCWA package I had a good sense of well-being.			.79
Since accessing the HCWA package I spend less time focusing on my child's future.			.78
The HCWA package has enabled me to spend more time focusing on my other child / children	.60		
After being involved in the HCWA package I have a better sense of well-being.	.57	.41	.57
I now have a better understanding of my child after accessing the HCWA package.	.65	.40	.46
The HCWA package offers me something as well as my child.	.69	.55	
All elements of the HCWA package helped my child.	.79	.41	
The HCWA package is aimed at assisting families (parents and children).	.66	.62	
I feel less anxious about my child after accessing the HCWA package.	.63		.55
I was able to follow up on the services in the home.	.67	.40	
The HCWA package is for children's learning.	.63	.40	
The HCWA package has made a difference to my child with an ASD and my family.	.81	.45	
The HCWA package services were easy to access.	.53	.64	
The services were locally available.	.36	.48	
Since accessing the HCWA package I am more confident in taking my child outside the family home and undertaking recreational activities with him / her.	.64	.55	.32
I use ideas and strategies from the HCWA package.	.31	.82	
The services provided were appropriate for my child.	.71	.61	
The HCWA package has confirmed for me that I am a good parent.		.80	
The HCWA package enables/enabled me to understand my child's behaviour better.	.52	.73	
The people providing the services communicated well with me	.41	.72	
The people providing the services communicated well with my child	.45	.76	
The HCWA package has increased my understanding of my child's ASD.	.72	.50	.317
I would recommend the services I received to others.	.54	.75	
I received value for money from the services provided.	.71	.36	.39
I had time to talk with the service providers.	.52	.34	
The HCWA package has increased the level of harmony in the home	.70	.58	
I have benefitted from the HCWA package	.78	.46	
My child with ASD has benefitted from the HCWA package.	.73	.56	
Others in the family/home have benefitted from the HCWA package	.79	.35	

Reviewing Table 4, the first and main factor was parents reported that the HCWA package assisted their child, with some of the strongest question/items loading on this factor being: *The HCWA package helps/helped prepare my child for school. Others in the family/home have benefitted from the HCWA package and The HCWA package has made a difference to my child with an ASD and my family.*

The second factor loads on questions that pertain to the notion that package enhanced their self-efficacy as a parent and their competency with their child, for example the following two items had a high loading on this factor: *The HCWA package has given me information and ideas on how to help my child. I use ideas and strategies from the HCWA package.*

The third and smaller factor related to the perception by parents that the HCWA package reduced their stress and anxiety, with the following item demonstrating a strong negative relationship to this factor: *Prior to being involved in the HCWA package I had a good sense of well-being.*

As identified in Table 4, while the data are supportive of a three factor solution, factor 1 and 2 are interactive with a number of the items having a strong loading on benefiting the child and the parents' self-competency and self-efficacy. This is, in part expected as many of the elements of the HCWA package were directly and indirectly targeting enhancing the parents' ability to cope with, and understand, and support their child with ASD. The factor structure lends support to the claim that there is a reciprocal interaction between each of the three factors with each factor positively influencing the other factors. The indicators are that enhancing children's performance and parents' understandings of their child enhanced parental self-efficacy which is linked to a reduction of parental stress and anxiety. Therefore,

it may be extrapolated from this data that the HCWA package contributed positively to the experience of parenting a young child with an ASD.

Part C

Participants' responses to the program using open questions.

Looking first at the services accessed via HCWA package (see Table 5), the respondents accessed the services of speech language pathologists more than any other service. The parents also reported that during the time they accessed the HCWA package and also indicated that they would use this service more frequently than other services if the HCWA package were unavailable. Access to occupational therapy was the second most likely service to be accessed both during the period of the HCWA package and if the package were unavailable. The least likely service to be accessed by respondents was the Autism advisor service.

Table 5

Average Level of Services Accessed in the HCWA Package

Services	How many time did you access HCWA? (Group Mean)	How many times was HCWA unavailable? (Group mean)
Psychologists	5.89	1.1
Speech Language Pathologists	50.47	4.68
Occupational Therapists	40.16	1.47
Autism Advisors (Autism Tas)	2.63	0.42

Note. based on access period of HCWA package as identified by respondent

Access to other services

The parents of children with ASD continued to access other services as well as the HCWA services, as shown in Table 6. The State Government's *Early Childhood Intervention Service*

was the most frequently utilized non HCWA service followed by support groups provided by Autism Tasmania. Both of these services were at no cost to the parent services provided to parents who had children with a variety of disabilities.

Table 6

Average Number Of Other Services Independant Of HCWA

Non HCWA Services	Average Number of times services accessed (group Mean)
Early Childhood Intervention Services (ECIS)	32.84
Support groups associated with Autism Tasmania	5.2

Open ended responses

The parents were asked to respond to five open ended questions where the parents had to write their responses in the survey. The first questions pertained to their concerns and the other four questions related to the HCWA services provided

Parental concerns pertaining to their child with an ASD

The parents' reported that issues with communication were ranked as the most frequently cited concern (see Table 7). Issues relating to behaviour, sensory difficulties and school were the next most commonly reported concerns by parents, followed by concerns about their child and social skills. Few respondents indicated issues with seizures, diet, motor skills, toilet training, childhood anxiety or routine.

Table 7

Identified Parental Concerns Pertaining To Child With An ASD By Of Concern

What is your main concern associated with your child?	Frequency
Communication	10
Behaviour	5
Sensory issues	5
School issues	5
Social skills	4
Community access	2
Lack of awareness of danger	2
Seizures	1
Limited diet	1
Fine and gross motor skills	1
Toilet training	1
Anxiety	1
Rigidity of routine	1

Four open ended questions about program.

The parents were asked to respond to four open ended question on the HCWA package, where the participants had to write their responses to each question. The four questions were: (1) What do you like best? (2) What do you like least? (3) How could the package be improved for your child? and (4) How could the package be improved for you? The parents' responses are reported in Table 8. This table was developed by a tabulation of themes in responses, where each written response to each of the questions was read and grouped by the theme of like content.

Participants reported the choice and access to services most appealing about the HCWA package. The least liked aspect of the service was its withdrawal after seven years of age. Respondents indicated that continuing the funding beyond the age of seven years would improve the package substantially for both themselves and their child.

Table 8

Common Theme Responses By Parents About Services N=19

Question	Responses	Frequency
What do you like best?	Choice and access to services	16
	The capacity to purchase resources	3
	Lump sum payment for rural families assisted with travel	1
	Access to experts	1
What do you like least?	Package withdrawn at age of 7 years	10
	Costs associated with travel or services	5
	Only one service provider	1
	No parent training / workshops	1
	Lack of evidence for some interventions	1
	Rules relating to how and when the funds could be spent	1
How could the package be improved for child?	Maintain the funding beyond 7 years of age	12
	Better access and quality interventions	1
	Less travel time	1
	More service providers	2
	Therapy in the home	1
How could the package be improved for you?	Continue the funding beyond 7 years of age	7
	Remove the need for justification of purchase of product	1
	Providers doing assessments in school	1
	Services in closer proximity to home	1
	Better understanding of therapies to help my child	1
	Capacity to self-monitor funds	1
	Access to respite	1
	Access to counselling	1

In conclusion

The findings associated with the parents' survey demonstrated that the HCWA package was positively supported by the parents who accessed it, they identified benefits for

their child, themselves and their family through their participation. They reported that they understood the condition better and gained greater sense of confidence and self-efficacy as a consequence of their involvement. Communication difficulties were perceived to be the parents main concerns associated with their child's development and there was strong support from the parents that the HCWA package and the funding initiative should extend beyond age seven.

Specific examples of parents' open ended responses will be explored as part of the following chapter (Chapter 5, The Discussion). The inclusion of these responses in the discussion is to better link the parents' responses to the wider academic literature, particularly the research literature reported in Chapter 2.

Chapter 5 - Discussion

This study sought to examine the extent to which accessing the HCWA package ameliorated parental stress. In doing so information was also gathered in relation to how parents perceived the quality or worth of the package. The results from this study provided compelling evidence that participating parents perceived the package to have been beneficial to their child and to the process of parenting a child with ASD. The study also provided both confirmation of the research literature in relation to parental stress and parenting a child with an ASD and a unique contribution to the literature by identifying elements of the HCWA package that may increase parental stress or require review.

5.1 Current Findings

The data from the PPQ survey instrument supported three themes in how the parents perceived and valued the HCWA package. The first theme was the HCWA package was seen as a way of assisting their child. The second theme was that parents reported that the package enhanced their competency as parents. The third theme related to the perception by parents that the HCWA package reduced their stress and anxiety. Each of these themes will be reviewed in more detail in the following section.

5.2.1 Theme 1: Parental concerns and support

Based on the open ended questions, the parents were specifically concerned about the communication and behaviour of their children with ASD and how services could be provided to assist their children and themselves with these concerns. It is interesting that these were the main concerns because the cohort of children with ASD in this study was not at the severe end of the continuum. The level of severity of their child's ASD was moderate

with only two respondents indicating that the level of severity of their child's ASD was moderate to severe. Such findings, however, support the notion that a range of educational and support services need to be provided to children with ASD and their families across the ASD continuum (Roberts & Prior, 2006; Mao, 2012; Schieve et al., 2010; Walsh et al., 2013).

The parents in this study identified enhancing communication with their child as one of the most important outcomes of their participation in the program. The response, *The HCWA package helps /helped my child communicate better* was in the top five outcomes on the survey. Poor communication and associated behavior issues can have several restrictive implications for the child and the parents' ability to manage their child (Wallace & Rogers 2010; Walsh et al., 2013). The parents also rated high on the question that *The HCWA package has made a difference to my child with an ASD and my family*. This supports the idea that as the child improved so too did the family dynamics and the social interactions with the child. This is an important recognition of the links between proactive interventions that focus on the skills development of the parents which thus encourage the parents to develop their self-efficacy as parents (Kersh et al., 2006) which then directly and indirectly enhanced the family interaction patterns and so enhance the parents' sense of greater control over their child's behaviour with ASD (Hastings & Brown 2002). The proactive nature of the intervention and its focus on strengthening the coping strategies of the parents as well as on enhancing the skills level of the child is an important aspect of the HCWA program that needs to be highlighted. It also validated the argument that services need to be integrated and support the family unit rather than just working and engaging in intervention with the child in isolation (Paynter, et al., 2008; Wallace & Rogers 2010; Zablotzky et al., 2012).

There is, however, divergence in the literature in relation to the origin of the parental concerns and stress associated with having a child with ASD. Certainly, the parent responses in this study support this notion that there is divergence of concerns and causes of stress for parents who have a child with ASD. As already reported the concern factor is not singular but is in fact multi-dimensional and includes: the permanency of the child's condition (Walsh et al., 2013; Sharpley et al., 1997); unevenness in cognitive and communication functioning and impairments in human relations (Dunn et al., 2001); cognitive functioning (Baker, 2003); lack of independence (Bitsika et al., 2004); diagnosis and severity of ASD (Mak et al., 2007; Davis et al., 2008); and time since diagnosis (Benson B et al., 2008).

The permanency of ASD was also cited frequently by respondents in relation to the parents fear that there would be a withdrawal of 'support and funding once their child with ASD reached the age of seven. How they were going to manage with their child with ASD after that point was a recurring concern. O'Brien's (2007) assertion that the diagnosis of an ASD is not a constrained experience but one that is irreversible was thus the sentiment of numerous respondents in the *Parental Perspectives Questionnaire*. Such a finding is also consistent with the research literature because a recurring theme in the research literature is the strong links between the child with ASD and that child's behavioural characteristics and the intensity, frequency and duration of parental coping and need for parental support (Benson et al., 2008; Gray, 2006; Lecavalier et al., 2006; Plant & Saunders 2007; Sheive et al., 2007; Tomanik et al., 2004; Zablotzky et al., 2012).

Similarly, the item that gained a very positive parental response was the parents' perceptions that the HCWA package did help to prepare their children for school. Such findings corroborate other researchers who have argued for the importance of early

intervention programs for children with ASD (Beamish 2008; Paynter et al., 2008; Wallace & Rogers, 2010). This finding also substantiates the argument that when nurturing young children with ASD one of the most significant transition points in the child's life is the transition from home to formal schooling (Prior et al., 2011). The perception from the participating parents was that the HCWA package had a positive influence on their child's transition from home to formal schooling is an important outcome of the HCWA funding. It also provides evidence of the relevance of this funding initiative from the Australian government and validates the need to maintain the HCWA package and its funding. While early intervention services may be seen as an initial significant financial cost, the evidence is that they are also imperative investments, for without these initiatives the ongoing and recurrence financial costs to the family, educational providers and adult community services will be significantly higher over time (Guralnick, 1997; Heckman, 2006; Seitz, Rosenbaum & Apfel, 1985). In particular, Heckman (2006) conducted a cost to benefit analysis of a number of early intervention studies and the follow up outcomes on the participating children, including a comparison of outcomes to similar non-intervention children. Heckman argued that early intervention financial "inputs" into the child strongly affected the need for later financial "inputs", such as additional educational services and later "outputs" such as a greater probability of productive employment of those children who received the early intervention. The claim is, that the cost to benefit ratio is balanced in favour of the early intervention.

5.2.2 Theme 2: Parental competency

Parental self-efficacy, self-confidence and self-esteem can be eroded in the face of the often unfamiliar and challenging child behaviours associated and the often ongoing and

unique demands of raising a child with ASD (Gray & Holden, 1992; Hay & Winn, 2012; Holroyd & McArthur, 1976; Winn & Hay 2005). In addition, it has been cited in the literature that parents of a child with an ASD often experience feelings of inadequacy, failure, shock, guilt, frustration, and resentment (Abidin, 1992; Bitsika & Sharpley 2004). In terms of this feeling, respondent 12 stated, *The package could include some funding for parents of carers to access counselors themselves.* This comment may well be in response to the significant impost raising a child with ASD has on an individual's beliefs about their skill as a parent, their capacity to cope and also the impact it places on marital and other relationships. Benson and Dewy (2008) concurred that parents with children with ASD experienced high levels of stress associated with child-related characteristics, and that these higher levels of stress were also associated with parents' perceptions of their own care-giving abilities. The fact that the parents' own support groups were well used by the parents in this study, and the parents gave positive comments about these services, in part, validates the need for these services.

Parental stress of parents with a child with ASD is considered to be multi-dimensional, with Tunali and Power (2002) suggesting it includes: (i) strained emotional relations within the family (e.g., overprotection, conflict); (ii) reduced social life (e.g., isolation, perceived social rejection); (iii) complexity and time burdens of the condition treatment; and (iv) parental grieving. Given Tunali and Power (2002) assertion, it is thus not unexpected that respondents to the PPQ questionnaire commented on the need for more counselling services and support and more case manager services and support.

5.2.3 Theme 3: Reduced stress and anxiety.

As noted above, elevated levels of stress for parents of children with ASD has been well documented in the research literature and one of the sources of stress is the cost and the

quality and ongoing adequacy of services (Benson et al 2008). These concerns were also identified by the participants and according to Respondent 16: *The short term nature of the package is disappointing. While we were introduced to some services that could have considerable benefit for our child, he is now too old to access the necessary funding to continue. This makes no sense.* Further to this, Respondent 13 stated: *The therapies used under the HCWA package helped my child and were expensive. Once the HCWA package ran out we felt we needed to continue as we had seen so much improvement. Thus back to financial stress.* Thus, it can be seen that parents reported considerable benefits from the HCWA package but conversely articulated elevated levels of stress once the service was withdrawn.

Twoy et al. (2007) maintained that the quality of case management of multidisciplinary professionals is an issue that needs to monitor when providing services to families with a child with ASD. This concern about case management was noted in the present study, in particular by Respondent 9, who stated: *This package was very useful and my son made major gains, but at times it was very difficult to co-ordinates [service] providers and we had no case management.* Consideration could be given in future iterations of the HCWA package to provide for an increased case management component to better organise and manage the different services and to allow for the setup of more case conference meetings where the child with ASD and the family can have input into the timing, duration and frequency of different services.

Access to social support and engaging with the wider community and recreational activities have been cited as potential buffers to parental stress and having a child with ASD (Bayat & Schuntermann 2013; Rivers & Stoneman 2003). This finding is supported in this

research with positive agreement to the survey item: *Since accessing the HCWA package I am more confident in taking my child outside the family home and undertaking recreational activities with him / her.* (Likert question 24 in the *Parental Perspectives Questionnaire* (Wilson & Hay 2011). This need for social outings was also articulated in the open ended survey questions with Respondent 11 stated, the need for *more social outings supported with groups support and help.* Given the research on the potential ameliorating effects of access to community and recreational activities, and these responses from the parents' surveyed, a future consideration of the HCWA package could be the inclusion of more group social outings for the parents.

5.2.4 Other factors that enhance wellbeing

The data derived from the survey also confirmed the perception that parents trusted the expertise and professionalism of the service providers and the service providers' capacity to interact with them as parents and improve the educational, social, language and physical outcomes for their children. Forming a positive working relationship between providers of the services and those who receive the services is considered a condition or criteria for effective interventions, and is a condition that needs to be actively encouraged and maintained by the service providers (Nation, Crusto, Wandersman, Kumpfer, Seybolt, Morrissey-Kane, & Davino, 2003).

The ability of participants to access a service is also a positive characteristic of effective interventions (Bird, Premkumar, Kendall, Whittington, Mitchell, & Kuipers, 2010). In terms of accessing services, the factor analysis of the survey results highlighted the cluster of variables which included the notion a sense of well-being as perceived by parents who accessed the HCWA package. This was also identified in the survey responses from the

participants who scored the following question high: *The HCWA services were easy to access.*

Given that parents reported that access to the HCWA package made a significant difference to their child and their family, it is not surprising that they wanted access to the service and the funding beyond the seven years of age cut off for their child with ASD. A concern expressed by the participants in this research was at the conclusion of the HCWA funding, they would not have the financial capacity to continue the intervention, or that continuing with the intervention placed an additional financial stressor upon the family in having to find the finances to maintain services. Thus in terms of access, the results from this study have provided strong evidence to attest to the notion while families are accessing the HCWA package their stress may be somewhat ameliorated, but at the conclusion of their access to the HCWA package, the lack of ongoing access to the package may in itself present as a significant antecedent to parental stress.

5.3 Suggestions for future research

Given the reality that fathers are underrepresented in the research literature on parental stress as well as the fact that in this cohort only two respondents were male, more emphasis should be given to encouraging fathers to participate in research. This would address the gender imbalance and create a more holistic approach to family support while being cognisant of parental stress. Studies by: Benson (2008); Bitsika et al. (2004); Gray (2003); Kersh et al. (2006); and Tunali (2002) have articulated the differences in coping styles and parental stress levels between mothers and fathers. Even so, more information is required to understand and address how to “close this gender gap” and more information is

needed on how to support parents both as individuals and as a couple in an ongoing relationship (Cappe et al., 2011). This may in turn reduce the significant number of families who because of a combination of factors break-up under the strain of attempting to nurture, comprehend, support and advocate for their child with ASD (Prelock, Calhoun, Morris, & Platt, 2011). While respite care was not a feature of this funding package its inclusion needs to be a consideration (Chan & Sigafoos, 2001) along with some family communication and stress and conflict management strategies (Prelock et al., 2011). The lack of social and emotional support is a risk factor for parents of children with ASD, and the incidence of single parent families is higher for this cohort of parents (Baker, 2005; Zablotsky et al., 2012). Thus, a single parent of a child with ASD is likely to need additional support, but how this is organised is still in need of more research.

5.4 Limitations and Future Research

The limitations of this study are in relation to the size and scope of the research. Due to the constraints of a small organization (Autism Tasmania) in a small state (Tasmania) the questionnaire distribution was limited and while the response rate was good, the sample size remained small. The *Parental Perspectives Questionnaire* used a combination of Likert and open ended questions, but no in depth parental interviews were conducted, which is a limitation in this study. The *Parental Perspectives Questionnaire* was designed specifically for the task of gathering data for the purposes of this research, but other instruments could have been considered or even used in addition to this single instrument. For example, in a related study to the one reported in this dissertation, Hall and Graff (2011) used the Abidi (1995) *Parenting Stress Index*, to investigate the behaviours of children with ASD, the level of family support, parenting stress, and parental coping. They too reported that parents of

children with ASD reported higher levels of parental stress and a higher need for support and coping strategies, compared with parents without a child with ASD.

Another limitation of the present study is the *Parental Perspectives Questionnaire* was administered once and at the end of the HCWA program. Ideally a range of pre-measures could have been considered before the program was started and these same measures repeated again at the end of the HCWA intervention to identify the psychological impact of the HCWA program on the participants. For example, administering to the participants the Abidi (1995) *Parenting Stress Index* as both a pre-intervention and as a post intervention measure. While such a pre and post measure would be of value, it was not the method selected to answer the research questions identified in this study, because the Abidi (1995) *Parenting Stress Index* is still a general parent stress measure, and not the focus of this research program evaluation. Even so, the inclusion of the Abidi (1995) *Parenting Stress Index* as part of an assessment procedure is a possible future research direction for future evaluation of the outcomes of the HCWA package.

This present study has focused on the short-term gains and the parents' perceptions of the HCWA early intervention package, however, the harder question to answer is: How do these programs enhance the opportunities and the development of the participating parents and children with ASD over the long-term? (Bird et al., 2010; Guralnick, 1997). Such evaluations are longitudinal and in this case future research evaluations could investigate parents' perceptions of the HCWA package over a longer period of time. Even so, evidence about the effectiveness of intervention programs is not that easy to collect because, in part, such evaluations assume a comparison between two similar cohorts of participants: those individuals who received the intervention and a similar cohort who did not receive the

intervention and there are ethical consideration and limitations in such a design (Bayat & Schuntermann, 2013; Whiteford, 2000).

In terms of future research related to HCWA package, the Prior and Roberts (2006) statement about early interventions and children with ASD is still valid. This is that for the majority of interventions, further ongoing evidence based research is still required to: (a) examine which children are most likely to benefit; (b) identify the most effective strategies for supporting their introduction and use; and (c) ascertain the extent to which a child's experience of a specific intervention fosters his or her general social cognitive and adaptive functioning.

Future research is, however, still needed on a number of levels in order to provide the hard evidence to change an often unresponsive government funding system to recognise the importance of interventions (Prior et al., 2011; Nation et al., 2003) and to have the evidence to challenge service providers to maintain best intervention practices to the consumers of those services (Matson et al., 2008; Pituch et al., 2011).

Chapter 6 – Conclusion

This research was, in part, designed to respond to the need articulated by Prior et al. (2011) for a greater monitoring of the effectiveness of the HCWA program from the parents' perspectives, and particularly from parents who live in rural and regional locations in Australia.

This study thus offers an extension to previous research and provides one of the few evaluative studies conducted on the HCWA package. Certainly, the findings are supportive of related research (Roberts & Prior, 2006; Wallace & Rogers, 2010) that has identified the value of such programs from both the parents' and the child's perspectives.

The study confirmed that parenting stress associated with having a child with ASD is considerable, often unremitting and multifaceted. The findings are supportive of Tway et al. (2007) who argued that unlike other "illnesses" or events, Autism is not short lived, but rather it is a lifetime of multidimensional issues that often place ongoing demands on the family. Despite this, parents of individuals with an ASD in this study also demonstrated that with support via the HCWA package, they can enhance their resilience to cope with having a child with ASD. The overall findings of this study are consistent with those researchers (e.g., Bayat & Schuntermann 2013; Cappe et al., 2011) who argued that parents of children with ASD require additional support and services and that these services and resources often need to be more specifically designed for this cohort of parents and their children with ASD.

One of the strongest outcomes of this study was the desire of the participating parents to have access to the HCWA package after their children with ASD past seven years of age. This reflects the reality that ASD is a lifelong condition that continues to impact on the child

with ASD and their parent, and managing the ASD condition requires ongoing support. The findings of this research highlighted challenges associated with parenting young children with ASD, while also affirming the parents' desire to provide the best possible start in life for their children with ASD. On this point, what Davis et al., (2002) stated is very relevant in terms of the findings in this study.

Parenting is a process of continual adjustment, potentially fraught with uncertainty. It involves a never-ending attempt to make sense of and adapt to a constantly changing situation, and yet it is often assumed to be natural. Little systematic preparation is provided, especially for those most in need, and subsequent accessible help is not universally available (Davis et al., 2002, p. 17).

The responses from parents participating in the HCWA package and collected through this research have affirmed that parents' valued participating in the program and that the parents maintained that their young children with ASD benefited from access to the program. The parents also verified that the two year HCWA package assisted in preparing their children for formal schooling.

The HCWA package has provided greater access to early intervention services by families with young children with ASD in Tasmania. Parents through this research have confirmed that they valued the HCWA package and initiative, as it enhanced their effectiveness in their parenting role and offered them information and services to support their children's development. The findings validate the notion that access to early intervention programs improves the developmental outcomes for the children involved and compliments and supports families in their parenting and care-giving responsibilities. These

results are based on a specifically designed survey of parents of young children with ASD who lived in rural and regional Australia.

References

- Abidin, R. R. (1992). The determinants of parenting behavior. *Journal of Clinical Child Psychology, 21*, 407-412.
- Abidin, R.R. (1995). *Parenting Stress Index: Professional Manual. 3*. Lutz: Psychologic Assessment Resources, Inc.
- Australian Advisory Board on Autism Spectrum Disorders (2007) *Prevalence Report* Commissioned Australian Advisory Board on Autism Spectrum Disorders from funding made available from the Commonwealth Department of Families, Community Services and Indigenous Affairs (FaCSIA).
- Baker, B. L., Blacher, L., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research, 4*(8): 575-590.
- Baker, B. L., McIntyre, L.L., Blacher, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4/5), 217-230.
- Bayat, M., & Schuntermann, P. (2013). Enhancing resilience in families of children with Autism Spectrum Disorder. In *Handbook of Family Resilience* (pp. 409-424). Springer New York.
- Bryer, F., Grimbeek, P., Beamish, W. & Stanley, A. (2004). How to use the *Parental Attitudes to Inclusion* scale as a teacher tool to improve parent-teacher communication. *Issues in Educational Research, 14*(2), 105-120.
- Beamish, W. (2008). *Consensus about program quality: An Australian study in early childhood special education*. Saarbrücken, Germany: VDM Publisher
- Benson, B., & Dewey, D. (2008). Parental stress and needs in families of children with Autism Spectrum Disorder. *International Journal of Disability, Community & Rehabilitation, 7* (1).Electronic Journal downloaded from <http://www.jdcr.cq>
- Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism and Developmental Disorders, 36*(5), 685-695.
- Bird, V., Premkumar, P., Kendall, T., Whittington, C., Mitchell, J., & Kuipers, E. (2010). Early intervention services, cognitive-behavioural therapy and family intervention in early psychosis: systematic review. *The British Journal of Psychiatry, 197*(5), 350-356.
- Bitsika, V. S., & Sharpley, C.F. (2004). Stress, anxiety and depression among parents of children with Autism Spectrum Disorders. *Australian Journal of Guidance and Counselling, 14*(2), 151 - 161.
- Boss, P. (2004). Ambiguous loss research, theory, and practice: Reflections After 9/11. *Journal of Marriage and Family. 66*, (3), 551, 516.

- Bowers, C.A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39-52.
- Cappe, E., Wolff, M., Bobet, R., & Adrien, J.L. (2011). Quality of life: A key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programs. *Quality of Life Research*, 20, 1279-1294.
- Chan, J. B., & Sigafos, J. (2001). Does respite care reduce parental stress in families with developmentally disabled children? *Child & Youth Care Forum*, 30(5), 253 - 263.
- Davis, H., Day, & C. Bidmead, C. (2002). *Working in partnerships with parents: The parent advisor model*. London: Harcourt Assessment.
- Davis, N.O., Day C., & Carter, A.S. (2008). Parenting stress in mothers and fathers of toddlers with Autism Spectrum Disorders: Associations with child characteristics *Journal of Autism and Developmental Disorders*. 38:1278-1291
- Dawson, G. (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. *Development and Psychopathology*, 20(3), 775.
- Dunn, E., Burbine, T., Bowers, C.A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39-52.
- Dunn, E. & Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social science and medicine*, 56(3), 631-642.
- Foreman, P., & Arthur-Kelly, M. (2008). Social justice principles, the law and research, as bases for inclusion. *Australasian Journal of Special Education*, 32(1), 109-124.
- Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social science and medicine*, 56(3), 631-642.
- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970-976.
- Gray, D.E., & Holden, W.J. (1992). Psycho-social well-being among the parents of children with autism. *Journal of Intellectual and Developmental Disability*, 18, (2), 83-93.
- Guralnick, M. J. (1997). Effectiveness of early intervention for vulnerable children: A developmental perspective. *American Journal on Mental Retardation*, 102(4), 319-345.
- Hall, H. R., & Graff, J. C. (2011). The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing*, 34(1), 4-25.
- Hastings, R. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual & Developmental Disability*, 27(3), 149-160.

- Hastings, R. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, 47(4/5), 231-237.
- Hastings, R., P., & Brown, T. (2002). Behaviour problems of children with autism, parental self-efficacy, and mental health. *American Association on Mental Retardation*, 107(3), 222 - 232.
- Hastings, R. P., Kovshoff, H., Ward, N.J., degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35(5), 635-644.
- Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioural intervention for their young child with autism. *Journal of Autism and Developmental Disorders*, 31(3), 327-336.
- Hay, I., & Winn, S. (2005). Students with Asperger's syndrome in an inclusive secondary school environment: Teachers', parents', and students' perspectives. *Australasian Journal of Special Education*, 29(2), 140-154.
- Hay, I., & Winn, S. (2012) High Functioning Autism Spectrum Disorder: A challenge to secondary school educators and the students with the condition, *Australian Association for Research in Education, Conference Sydney*.
- Heckman, J.J. (2006). Skill formation and the economics of investing in disadvantaged children. *Science*, 312(5782), 1900-1902.
- Herring, S. G., Taffe, K., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive and developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, 50(12), 874-882.
- Higgins, D. J., Bailey, S.R., & Pearce, J.C. (2005). Factors associated with functioning style and coping strategies of families with a child with autism spectrum disorder. *Autism*, 9(2), 125-137.
- Hill, A., & Hill, R. (2007). Evaluating development programs for parents of 0-4 year olds: Impacting parental stress and confidence. *E-Journal of Applied Psychology*, 3(1), 94-104.
- Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal of Mental Deficiency*, 80(4), 431-436.
- Kersh, J., Hedvat, T.T., Hauser-Cram, P., & Warfield, M.E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities *Journal of Intellectual Disability Research*, 50(12), 883-893.

- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172-183.
- Mak, W.S., Ho, A. H. Y., & Law, R.W. (2007). Sense of coherence, parenting attitudes and stress among mothers of children with Autism in Hong Kong. *Journal of Applied Research in Intellectual Disabilities*, 20, 157-167.
- Mao, A.R. (2012). Factors that contribute to caregiver burden for parents of children with Autism Spectrum Disorder or HYPERLINK "<http://www.jaacap.com/article/S0890-8567%2812%2900501-1/abstract>" Attention HYPERLINK "<http://www.jaacap.com/article/S0890-8567%2812%2900501-1/abstract>" -Deficit/Hyperactivity Disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51, 864-866.
- Matson, J. L., Wilkins, J., & González, M. (2008). Early identification and diagnosis in autism spectrum disorders in young children and infants: how early is too early? *Research in Autism Spectrum Disorders*, 2(1), 75-84.
- Matson, J. L., & Smith, K. R. (2008). Current status of intensive behavioral interventions for young children with autism and PDD-NOS. *Research in Autism Spectrum Disorders*, 2(1), 60-74.
- Nation, M., Crusto, C., Wandersman, A., Kumpfer, K. L., Seybolt, D., Morrissey-Kane, E., & Davino, K. (2003). What works in prevention. *American Psychologist*, 58(6), 449.
- O'Brien, M. (2007). Ambiguous loss in families of children with Autism Spectrum Disorders. *Family Relations*, 56 (2), 135-146.
- Oelofsen, N. & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability*, 31(1), 12-12
- Paynter, J., Scott, J., Beamish, W., Duhig, M., & Heussler, H. (2012). A pilot study of the effects of an Australian centre-based early intervention program for children with autism. *Open Pediatric Medicine Journal*, 6, 7-14.
- Pisula, E. (2007). A comparative study of stress profiles in mothers of children with Autism and Down Syndrome. *Journal of Applied Research in Intellectual Disabilities*, 20, 274-278.
- Pituch, K. A., Green, V. A., Didden, R., Lang, R., O'Reilly, M. F., Lancioni, G. E., & Sigafoos, J. (2011). Parent reported treatment priorities for children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 5(1), 135-143.
- Plant, K. M., & Saunders, M.R. (2007). Predictors of care-giver stress in families of preschool aged children with developmental disabilities *Journal of Intellectual Disability Research*, 51(2), 109-124. 1-12.

- Prelock, P. A., Calhoun, J., Morris, H., & Platt, G. (2011). Supporting parents to facilitate communication and joint attention in their young children with Autism Spectrum Disorders: Two pilot studies. *Topics in Language Disorders*, 31(3), 210-234.
- Prior, M., Roberts, J. M.A., Rodger, S., Williams, K., & Sutherland, R. (2011). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia.
- Rayner, M. M., S. (2007). Stress and ameliorating factors among families with a seriously ill or disabled child. *E-Journal of Applied Psychology*. 3(1): 86 - 93.
- Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33(4), 383-394.
- Roberts, J. M. A., & Prior, M. (2006). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Health and Ageing, Australia.
- Sarantakos, S. (2005). *Social research* 3rd ed. Plagrove: Macmillan Publishers.
- Saunders, J.L., & Morgan, S.B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: implications for intervention. *Child and Family Behaviour Therapy*, 19(4)15-32.
- Schieve, L. A., Blumberg, S.J., Rice C., Visser S.N, & Boyle C. (2007). The relationship between autism and parenting stress, *Paediatrics*, 119: 114-121
- Seitz, V., Rosenbaum, L. K., & Apfel, N. H. (1985). Effects of family support intervention: A ten-year follow-up. *Child Development*, 376-391.
- Sharpley, C. F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, 22(1), 19-28.
- Sivberg, B. (2002). Family systems and coping behaviours: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*, 6(4), 397-409.
- Smith, L. E., Seitzer., Tager-Flusberg, H., Greenberg, J.S., & Carter, A.S. (2007). A comparative analysis of well-being and coping among mothers of toddlers and mothers of Adolescents with ASD. *Journal of Autism and Developmental Disorders*.38:876-889
- Tomanik, S., Harris, G.E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability*, 29(1), 16-26.

- Tunali, B., & Power, T.G. (2002). Coping by redefinition: Cognitive appraisals in mothers of children with Autism and children without Autism. *Journal of Autism and Developmental Disability*, 32(1), 25-34.
- Twoy, R. C., Connelly, P.M., & Novak, J.M. (2007). Coping strategies used by parents of children with autism. *Journal of the American Academy of Nurse Practitioners*, 19, 251-260.
- Wallace K., & Rogers, S.J. (2010). Intervening in infancy: implications for autism spectrum disorders. *Journal of Child Psychology and Psychiatry*, 51, 1300–1320.
- Walsh, C. E., Mulder, E., & Tudor, M. E. (2013). Predictors of parent stress in a sample of children with ASD: Pain, problem behavior, and parental coping. *Research in Autism Spectrum Disorders*, 7(2), 256-264.
- Wang, P., Michaels, C.A., & Day, M.S. (2011). Stress and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of Autism and Developmental Disability*, 41(1), 783-795.
- Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Viecili, M., & Lunskey, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism*, 16(3), 261-274.
- Whiteford, E. H. (2000). Early intervention programs for children with autism: Conceptual frameworks for implementation. *American Journal of Orthopsychiatry*, 1(1) 82-9.
- Zablotsky, B., Bradshaw, C. P., & Stuart, E. A. (2012). The association between mental health, stress, and coping supports in mothers of children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 1-14.

Appendix A: Survey

Parental Perspectives Questionnaire

K. Wilson & I. Hay

The aim of this questionnaire is to collect information from parents on how they view the *Helping Children with Autism (HCWA) Package*. This questionnaire should take around 15 minutes to complete and your answers will be treated as confidential.

There are no right or wrong answers.

Date _____ Current age _____

Gender (Circle): Male / Female

How many children do you have? _____

Occupation _____

Occupation of partner (if applicable)

Participant's education level

How old is your child/children with a diagnosis of an ASD? _____

How long have you been accessing the HCWA package?

Which best describes your child - please tick one	
No real special needs	
Mild level of special needs	
Moderate level of special need	
High level of special needs	

Level of services accessed in the *HCWA package* were: (Please list here)

Service type	How often with access to HCWA?	How often if HCWA is unavailable?
Autism Advisor		
Speech therapist		
Psychologist		
Occupational therapist		

Did your access either of these services independent of the HCWA?

	How often?
Early childhood intervention service (ECIS)	
Support group	

What is your main concern associated with your child with an ASD _____

For each of the following statements rate your level of agreement from:

- 1 = strongly disagree
- 2 = disagree
- 3 = sometimes agree
- 4 = agree
- 5 = strongly agree

There are no right or wrong answers.

Please circle your agreement level to each of the statements below.

1. The *HCWA package* helps / helped prepare my child for school.

1 2 3 4 5

2. The *HCWA package* helps my child mix with other children of a similar age.

1 2 3 4 5

3. The *HCWA package* helps / helped my child communicate better.

1 2 3 4 5

4. The *HCWA package* helps / helped me understand my child's sensory needs better.

1 2 3 4 5

5. The *HCWA package* gives parents time to focus on their child.

1 2 3 4 5

6. The *HCWA package* helps/helped me become a better parent for my child.

1 2 3 4 5

7. The *HCWA package* helps / helped my child become more independent.

1 2 3 4 5

8. I am already aware of how to help my child.

1 2 3 4 5

9. The *HCWA package* has given me information and ideas on how to help my child.

1 2 3 4 5

10. Prior to being involved in the *HCWA package* I had a good sense of well-being.

1 2 3 4 5

11. Since accessing the *HCWA package* I spend less time focussing on my child's future.

1 2 3 4 5

12. The *HCWA package* has enabled me to spend more time focussing on my other child / children.

1 2 3 4 5

13. 8. After being involved in the *HCWA package* I have a better sense of well-being.

1 2 3 4 5

14. I now have a better understanding of my child after accessing the *HCWA package*.

1 2 3 4 5

15. The *HCWA package* offers me something as well as my child.

1 2 3 4 5

16. All elements of the *HCWA package* helped my child.

1 2 3 4 5

17. The *HCWA package* is aimed at assisting families (parents and children).

1 2 3 4 5

18. I feel less anxious about my child after accessing the *HCWA package*.

1 2 3 4 5

19. I was able to follow up on the services in the home.

1 2 3 4 5

20. The *HCWA package* is for children's learning.

1 2 3 4 5

21. The *HCWA package* has made a difference to my child with an ASD and my family.

1 2 3 4 5

22. The *HCWA package* services were easy to access.

1 2 3 4 5

23. The services were locally available.

1 2 3 4 5

24. Since accessing the *HCWA package* I am more confident in taking my child outside the family home and undertaking recreational activities with him / her.

1 2 3 4 5

25. I use ideas and strategies from the *HCWA package*.

1 2 3 4 5

26. The services provided were appropriate for my child.

1 2 3 4 5

27. The *HCWA package* has confirmed for me that I am a good parent.

1 2 3 4 5

28. The *HCWA package* enables / enabled me to understand my child's behaviour better.

1 2 3 4 5

29. The people providing the services communicated well with me

1 2 3 4 5

30. The people providing the services communicated well with my child

1 2 3 4 5

31. The *HCWA package* has increased my understanding of my child's ASD.

1 2 3 4 5

32. I would recommend the services I received to others.

1 2 3 4 5

33. I received value for money from the services provided.

1 2 3 4 5

34. I had time to talk with the service providers.

1 2 3 4 5

35. The *HCWA package* has increased the level of harmony in the home

1 2 3 4 5

36. I have benefitted for the *HCWA package*

1 2 3 4 5

37. My child with ASD has benefitted from the *HCWA package*.

1 2 3 4 5

38. Others in the family / home have benefitted from the HCWA package

1 2 3 4 5

39. What do you like **best** about the HCWA package? Please make a comment below.

40. What do you like **least** about the HCWA package? Please make a comment below.

41. How could the HCWA package be **improved for your child**? Please make a comment below.

42. How could the HCWA package be **improved for you**? Please make a comment below.

Once again – thank you for completing this questionnaire.

Appendix B: Introduction Letter

Introduction Letter for the CEO Autism Tasmania

and the *Autism Advisor*

Hello, my name is Kate Wilson. I am a registered teacher working as an Autism Consultant who is working towards a Master of Education (Research) qualification, through the University of Tasmania, under the supervision of Professor Ian Hay, Dean of the Faculty of Education. As a part of my research for completing my thesis, I am investigating parental perspectives of the Helping Children with Autism package.

What does the study involve?

The study involves parents completing a short questionnaire. The answers from the questionnaire will provide information which will assist in better understanding what parents' think about the Helping Children with Autism package.

Who will be invited to participate in this study?

Parents who have been involved with the Autism Advisor service with Autism Tasmania, will be invited to participate in this study. Parents will be provided with an information sheet and a written consent form, prior to being invited to complete a short questionnaire, which should take less than ten minutes to complete. All documentation is attached for your reference.

Consent and Confidentiality?

Parental involvement in this research is voluntary and any parent may withdraw at any time without giving a reason. The information collected through this research will be treated in confidence and stored under electronic password protection.

What will happen to the results of this research?

The findings from this research will be contained within a thesis for the Faculty of Education, University of Tasmania, as part of the requirements for a Master of Education (Research), due for presentation by December 2011.

How can I ask a clarifying question in relation to this research?

If you would like to discuss any aspect of this study please feel free to contact me on 62311625 or 0417372652. I would be happy to discuss any aspect of this research with you.

Thank you for taking the time to read this information sheet and I hope you will consent to supporting this research.

Thank you and kind regards

Kate Wilson; with approval from Professor Ian Hay, Dean, Faculty of Education, UTAS

Attachments: *Parental Perspectives Questionnaire*