Psychosocial Factors and the Health of Parents

LIST OF PAPERS

This thesis incorporates the following four original empirical papers:


In addition the following abstracts arose from conference presentations:

Psychosocial Factors and the Health of Parents


European Association of Social Psychology Summer School

In August 2012, I was accepted to and attended a two week PhD summer school. The workshop stream in which I participated was “Social identity and health”; this was headed by Professor Alex Haslam, Dr. Stephen Gallagher and Dr. Aisling O’Donnell.
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ABSTRACT

The focus of this thesis was to identify psychosocial factors associated with the variance in health outcomes for parents of children with disabilities. The approach taken was in line with a recent paradigm shift from identifying factors predictive of psychological distress to one of exploring factors that buffer parents from the stress of caring and thus serve a protective function for parental health. A role identity framework was identified as a promising method of exploring the underlying pathways to the maintenance of protective factors. Resources associated with the successful evaluation of role identities are mastery and self-esteem, thus in the first study and the two empirical papers that emerged from this study, the part that these resources play in health outcomes for parents was established. The results suggest that higher levels of these resources are beneficial for psychological and physical health but the relationships between these factors and other established risk and protective factors, i.e. stress and social support, are complex and nuanced. The data reported in the third paper, which emerged from the longitudinal study, highlight the constancy of poorer parental psychological well-being over time. The benefit of roles such as employment in maintaining better psychological well-being was supported. The fourth paper explored the associations between role identity processes and parental psychological well-being. The results suggest that multiple roles, role balance and roles outside of the caring role were associated with less depressive symptomology. Of the role identity processes role balance predicted the greatest variance in depressive symptomology however perception of performance in roles outside of caring, irrespective of the type of role, predicated less depressive symptomology. These findings suggest that for parents of children with disabilities managing a smaller number of identities but having one outside the parenting role which provides a method of self-evaluation is important to psychological well-being.
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DECLARATION

The substance of this thesis is the original work of the author and due reference and acknowledgement has been made, where necessary, to the work of others. No part of the thesis has been submitted in candidature of any degree. The candidate was the primary author of the four empirical papers.

____________________

Joanne Cantwell

(Candidate)
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A big thanks to all of the psychology post-grad community who provide tremendous support to each other, most of us have needed it at some point and there was always someone to provide even a listening ear when it was needed. To those who went before, Rachel and Sarah, to my cohort Catherine and Brenda, and to everyone else, thanks for all your help. Thanks to Eoin, for being a formatting whiz.

Last and not least, great big thanks to Molly my greatest cheerleader, for your understanding and support throughout.
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<td>ASD</td>
<td>Autism spectrum disorder (ASD) describes a group of disorders that includes autism, Asperger's syndrome and pervasive developmental disorder (also known as atypical autism).</td>
</tr>
<tr>
<td>Autism</td>
<td>Autism is the most commonly occurring form of ASD. A neurodevelopmental disorder characterized by impaired social interaction, verbal and non-verbal communication, and restricted and repetitive behavior.</td>
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<tr>
<td>Complex needs</td>
<td>A person with ‘complex needs’ is someone with two or more needs affecting their physical, mental, social or financial wellbeing. These needs are often interrelated or interconnected and may be profound, severe, serious or intense.</td>
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<tr>
<td>Developmental disability</td>
<td>A developmental disability is a diverse group of chronic conditions that occur before the age of 22. These disabilities substantially impact the individuals daily life and can significantly impair general intellectual and /or adaptive functioning</td>
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<td>Downs syndrome</td>
<td>A congenital disorder arising from a chromosome defect, causing intellectual impairment and physical abnormalities including short stature and a broad facial profile. It arises from a defect involving chromosome 21, usually an extra copy (trisomy-21).</td>
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<tr>
<td>Intellectual disability</td>
<td>The term used to describe a significant impairment of intellectual functioning and adaptive behavior limitations identified prior to age 18.</td>
</tr>
<tr>
<td>Learning disability</td>
<td>Significantly reduced ability to understand new or complex information, to learn new skills and reduced ability to cope independently which starts before adulthood with lasting effects on development. A learning disability can be mild, moderate or severe.</td>
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<td>Special needs</td>
<td>Term used to describe individuals who require assistance for disabilities that may be medical, mental, or psychological. Types of special needs vary in severity. People with autism, Down syndrome, dyslexia, blindness, ADHD, or cystic fibrosis, for example, may be considered to have special needs.</td>
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CHAPTER ONE

INTRODUCTION

“He can’t walk or talk. But he smiles a lot”

Why Parents of Children with Disabilities

In recent decades the move from a model of institutional care to one of inclusion (i.e., home and community ambulatory care) plus advances in transportable medical equipment, has meant that people with intellectual disability and chronic illness are more likely to live in the home setting (Van Dyke & Allen, 1990). As a consequence, there is an increased likelihood that one will experience caring for a family member or friend across the lifespan. Currently 187,112 individuals in Ireland (4.1% of the population) report providing regular unpaid personal help for a friend or family member with a long term illness, health problem or disability (including old age, Central Statistics Office; CSO/2011). This figure is considered to vastly under represent the actual number of people providing care for family members as many family carers, including young carers, do not recognise themselves as such, many believing that they are fulfilling a normal and expected familial role (Kutner, 2001; Ward & Cavanagh,1997). Additionally, it is not clear how many of the parental carers for the 66,437 children under the age of 19 with a disability\textsuperscript{2} are represented in this figure (Brooks, Gavin, Meaney, & Roche, 2012).

In Ireland, as is the case internationally, most individuals (97.2\%) under the age of 19 with a disability reside in a home setting, the majority being cared for by either one or both parents (Braddock, Emerson, Felce, & Stancliffe, 2001; Kelly, Craig, & Kelly, 2010). Only

\begin{footnote}{\footnotesize \textsuperscript{1} Quote written on the survey by a mother (49) of one child, a boy age seven with mitochondrial disorder \textsuperscript{2} The use of the term “disabilities” is broad and intended to cover all disabilities including developmental disability (DD), intellectual disability (ID), and chronic health problems (CHD). If a study indicates the type of disability i.e. DD, ID, ASD, CHD this will be explicitly stated.\end{footnote}
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1% of children under the age of 14 with a disability do not live in a private household (CSO, 2011), suggesting that the majority are cared for in the family home. The most prevalent form of caring is parent carers (92%) and within this cohort two parent families are the norm, however this trend has slowly changed over the last few decades with many parents now caring alone (Brown et al., 2008). Olsson and Hwang (2001) found that single mothers of children with disabilities were more vulnerable to the stresses of caring.

Extensive research conducted on health outcomes of parents of children with disabilities has consistently indicated that parenting atypically developing children can impose burdens beyond the normal stresses associated with the parenting role (Dyson, 1997; Emerson, 2003). The added stress of parenting a child with disabilities is driven by caregiver burden, a composite of the objective and subjective strains associated with the caring role. These strains include tasks such as assisting with activities of daily living, disruption to everyday life in the household, limitations on employment, financial problems, uncertainty about the child’s health, accessing services, worry about the future and disruption to personal activities and social interactions (Cramm & Nieboer, 2011; Murphy, Christian, Caplin, & Young, 2007).

Exposure to increased stress levels poses a substantial threat to parental health. Moreover given that the Centre for Disease Control and Prevention (CDC) report increases in developmental disabilities such as autism to be the fastest growing developmental disability (DD) in the United States (119.4% increase from 2000 to 2010; CDC, 2014b) these trends taken together signify a major public health concern. Therefore, these numbers of parents caring for children with disabilities represent a sizeable challenge, particularly as these parents will potentially be in this caring role for a longer period of time.

Parental well-being is inextricably linked to the well-being of their children; the needs of parents are often interpreted and articulated as relating to their children. However when
the needs of their children are not met by the service system, the resources of the parent are applied to finding ways of accessing services for their children. This frequently means their own needs are ignored, often leading to burnout and, inevitably, health problems (Murphy et al., 2007). Significantly, poorer parental psychological health has been implicated in maladaptive outcomes for children under their care. A reciprocal relationship between parent and child often means that the behaviour and needs of the child may drive parental strain and distress which can then impact the child through maladaptive and often problematic parental practise and behaviour (Hastings & Brown, 2002; Micklewright, King, O'Toole, Henrich, & Floyd, 2012; Neece, Green, & Baker, 2012; Thurston et al., 2011). Furthermore, children of distressed parents have been found to be at greater risk of maltreatment, neglect and physical abuse (Spratt, Saylor, & Macias, 2007).

Similarly, poorer parental physical health may impact their ability to work, take care of the child with a disability, manage social relationships and if applicable, may affect the well-being of the family as a whole (McKeown, Haase, & Pratschke, 2003). Poorer parental health has also been found to be associated with recurrent hospitalisation (Kelly & Hewson, 2000) and unwanted decisions to place the children out of the home (Bromley & Blacher, 1991). Parental health is vital for the sustainability of care and given the likely family, public health and economic costs of ill health parental health should be a key concern; not only for their own quality of life but also due to the consequences maladaptive health outcomes have on those under their care. Finally, the significant negative consequences of elevated distress for parents are such that much of the research conducted on the health of parental carers is aimed at identifying factors which underlie the variability in differential susceptibility to distress. The focus is on gaining an understanding of the individual difference in resilience with the aim of developing new approaches and improving services for parents.
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CHAPTER TWO

REVIEW OF THE LITERATURE

Existing Knowledge on the Health of Parents of Children with Disabilities

Researchers acknowledge that many parents and families fare well when caring for a child with disabilities (for review see Horsley & Oliver, 2015). Parents report personal improvements, appreciation of the simple things in life, positive feelings about caring for a child with a disability and a closer and stronger family as a result of having a child with disabilities (Caples & Sweeney, 2010; Cohen, Colantonio, & Vernich, 2002; Hastings, Allen, McDermott, & Still, 2002; Hilgeman, Allen, DeCoster, & Burgio, 2007; McConnell, Savage, Sobsey, & Uditsky, 2015; Schwartz, 2003). However, despite the recognition that there are positive aspects to the caring experience, over the past 30 years a substantial body of interdisciplinary research has supported the costs of caring on parental health. Much of the earlier research examined the mental health consequences of caring on parents, but more recently research on the physical and cognitive costs of caring have increased (e.g., Gallagher, Philips, Drayson, & Carroll, 2009a; Lovell, Elliot, Liu, & Wetherell, 2014; Lovell, Moss, & Wetherall, 2012; Lovell, Moss, & Wetherall, 2015; Ruiz-Robledillo, Belostabatalla, & Moya-Albiol, 2015; Ruiz-Robledillo & Moya-Albiol, 2013). Combined, these studies provide considerable support for the increased morbidity associated with caring for a child with disabilities.
Theoretical Frameworks Employed in Research on Parental Health Outcomes.

A number of frameworks have been employed in research to examine outcomes for parents of children with disabilities (Raina et al., 2004). Two of the most popular models are the Double ABCX (McCubbin & Patterson, 1983) and the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). Caring for a child with a disability is a complex, dynamic, multidimensional process and the Double ABCX model, an extension of the first multivariate model to deal with this dynamic family stress process (ABCX; Hill, 1949), is one of the dominant models in guiding caregiver research. According to this model, adaptation is determined by the interaction of the stressor (the child with a disability) and subsequent life events such as existing and new resources, parental perceptions and coping resources (see Fig. 1).

All elements of the model have individually been found to be associated with parental carer outcomes. Severity of the stressor (a) which could include having a child with a disability who has additional behavioural problems (Sipal, Schuengel, Voorman, Van Eck, & Becher, 2010), child behaviour problems (King, King, & Rosenbaum, 1999), mental illness combined with a somatic illness (Hastrup, Van Den Berg, & Gyrd-Hansen, 2011), severity of disability (Leonard, Johnson, & Brust, 1993) and a delay in and the ability to communicate (Emerson, Robertson, & Wood, 2004). Over time a pile-up of demands or accumulated stressors (aA), which may not necessarily be related to (a) but may exacerbate the stress of such, may occur (e.g., birth of additional children, job loss, divorce, death of a family member, additional family illness). Existing (b) and expanded (B) resources refer to resources which have been put in place around the initial stressor (e.g., respite, home help, social support) and how they change and develop over time (e.g., longer respite, attending parental/sibling support groups or counselling). Additionally, parents may take on new roles (e.g., as a full time carer) and lose other roles (e.g., job, hobbies, social life), which may be
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necessary to cope with the responsibility of caring but in some cases may add to their distress. Subjective appraisal of the cause of the crisis (c) and how this is affecting them over time (C) is highly related to parental outcome (Minnes, Woodford, & Passey, 2007). Finally, coping (BC) is seen as the behavioural response to the interaction of stressor (xX), resources (bB) and perceptions (cC).

Figure 1. Double ABCX Model (McCubbin & Patterson, 1983)

Another widely employed model in parental research is Lazarus and Folkman’s (1984) Transactional Model of Stress and Coping which suggests internal and external resources are influential in determining an individual’s stress appraisals. This cognitive phenomenological theory of stress, views stress as a person–situation transaction; the situation itself is not inherently stressful but is dependent on a subjective cognitive judgement of the situation by the individual. The primary appraisal of a stressor is influenced by the personal (sociological and psychological) resources of the individual, these have been found to be more stable across situations, whereas the secondary appraisal is influenced by the physical and social environment which is more context specific (Folkman, Lazarus, Dunkel-
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Schetter, DeLongis, & Gruen, 1986). Central to both these models and what they have in common is that parental appraisal of the stressful situation is highly predictive of outcomes. Moreover, resources both internal (e.g., coping styles) and external (e.g., social support) are factors that influence stress appraisal and ultimately health. In fact, Kuipers, Onwumere, and Bebbington (2010) suggest that appraisal of their situation and coping resources are more crucial than the severity of the stressor. Saloviita, Itälinna, and Leinonen (2003) found that for parents of children with DD the negative appraisal of the situation was the single most important predictor of parental stress. For mothers, the negative definition was associated with the behavioural problems of the child while, in fathers it was connected with the experienced social acceptance of the child. Plant and Sanders (2007) suggest that parental appraisal is a better predictor of parental stress than child behaviour problems. Moreover, a parent's cognitive appraisal of their child's level of disability directly influenced their level of stress. Manning, Wainwright, and Bennett (2009) found that reframing, a cognitive appraisal strategy, can lead to positive affect by allowing a parent to see the situation in a more positive light. Coping strategies instigated following appraisal affect the level of psychological distress and poorer health experienced by parents (Glidden, Billings, & Jobe, 2006; Hastings et al., 2005; Higgins, Bailey, & Pearce, 2005). Positive strategies such as active coping (Jones & Passey, 2004) and problem focused coping (Kenny & McGilloway, 2007) are related to better adjustment and healthier parental outcomes while maladaptive coping strategies include denial, disengagement (Kim, Greenberg, Seltzer, & Krauss, 2003) and emotion-focused coping which have been shown to predict greater subjective burden and depression.

Although the Double ABCX has been shown to account for substantial variance in parental adaptation (Manning et al., 2009; Stewart & McGrew, 2009) it does have its limitations. The Double ABCX looks to explain family adjustment, the real focus is on the
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primary carer’s (most often the mothers) individual perceptions of these family resources, which can be influenced by their own psychological resources such as self-esteem, trait personality factors linked to coping (e.g., levels of mastery). Therefore, factors such as role identities may influence the well-being of the primary carer through influencing self-esteem and mastery. Thus, individual characteristics of the primary caregiver will be a major contributor to family resources, interpretation of resource availability, parental outcomes and as a consequence family adaptation. Similarly, some of the concepts associated with ABCX such as taking on new roles and what their implications are for coping or parental health are under specified. The underlying pathway to the successful maintenance of some of these beneficial protective factors (such as self-esteem and mastery), which may mediate caregiver stress (Jones & Passey, 2004) is yet to be explored. Thus, in the present thesis the aim is to extend on this theoretical knowledge by testing the interactive and synergistic pathways underlying these caregiver stress-health associations.

Psychological Costs of Caring for Parents of Children with Disabilities.

Extensive research conducted on the mental health costs of caring for a child with disabilities provides unmitigated support for the poorer psychological well-being experienced by parents (Barker et al., 2011; Giallo, Wood, Jellett, & Porter, 2013; Raina et al., 2005). The higher perceived stress reported by parents is associated with higher distress and poorer psychological health (Emerson et al., 2004; Oelofsen & Richardson, 2006). Issues such as anxiety, low self-esteem, poorer general emotional health and pessimism about the future (Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Hastings, Daley, Burns, & Beck, 2006; Lam, Giles, & Lavander, 2003; Olsson & Hwang, 2001; Singer & Floyd, 2006) are all more apparent for parents of children with disabilities compared to parents of typically developing children. However, much of the research on parental mental health explores depression as an
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outcome, perhaps due to the far reaching implications of depression on all aspects of life for the sufferer (Benson, 2006). Parents suffering from depression are often withdrawn, disengaged, hostile, colder, feel less parental efficacy, have more negative appraisals of the child’s behaviour and often use authoritarian parenting practices (Cyranowski, Swartz, Hofkens, & Frank, 2009; Najman et al., 2001). Thurston et al. (2011) found that of a sample of 429 parents of children with complex needs, 42% exhibited symptoms (mild to severe) of psychiatric distress. These symptoms were associated with a range of issues from poorer social support, family dysfunction, greater adverse impact of the child's situation on the family, poorer child behaviour, unfavourable parenting styles to poorer child psychosocial functioning. Depression is a debilitating condition that can leave sufferers with difficulty in caring for themselves and also in carrying out caring responsibilities. Moreover, the depressed parent may find it difficult to adhere to interventions which require drive and energy on their part to implement. Rates of depression have been found to be higher in parents caring for children with disabilities compared to parents of typically developing children (Smith & Grzywacz, 2014). For example, in one UK study, 59% of parents caring for a child with autism had scores on the General Health Questionnaire indicative of psychiatric caseness (Bromley, Hare, Davison, & Emerson, 2004). Similarly, in another U.K. sample of parents of children with DD, two-thirds of parents met the conventional criterion for possible clinical depression (Gallagher, Phillips, Oliver, & Carroll, 2008). However, rates from population based-studies are relatively lower albeit still higher than those of parents of typically developing children. Gallagher and Hannigan (2014) examined data from an Irish population based cohort which suggested that the prevalence rate of depression was significantly higher for parents of children with DD than for control parents. Moreover, the treatment rates for depression were similar for both groups of parents suggesting parents of
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children with DD were not receiving (or seeking) treatment, further proof that parents may not be attending to their own health needs.

Although the evidence for poorer psychological health in parents is now well established, the majority of this research comes from cross-sectional studies with longitudinal research designs being more limited. Consequently changes in parental psychological well-being and the factors which influence this variation over time are not fully understood. The available longitudinal studies report the constancy or increase in poorer psychological well-being over time. Olsson, Larsman, & Hwang (2008) explored psychological well-being of parents of children with DD over one year. They found that psychological well-being for parents of children with DD was relatively constant across the time of the study and also was worse than control parents at baseline and at the one year mark. Likewise, in a study conducted over a ten year period, evidence for poorer psychological well-being increasing significantly over this time span was found (Smith & Grzywacz, 2014). Finally, given the paucity of longitudinal studies in this area, one of the main aims of this thesis will be to contribute to this body of knowledge by conducting a longitudinal study but importantly assess the predictors of well-being over time in these parental carers.

Physical Health Costs of Caring on Parents of Children with Disabilities

While the bulk of research has been on the psychological outcomes of parents, acknowledgement of the risk that distress plays in physical health has meant that research attention has recently incorporated parental physical health. Psychological stress may heighten the risk of an individual being more vulnerable to physical diseases such as cardiovascular, autoimmune and cancer (Gallagher & Hannigan, 2014; Olsson & Hwang, 2008). Moreover, parents of children with disabilities are more likely to self-report their health as poor or below average (Brehaut et al., 2009; Eisenhower, Baker, & Blacher, 2009).
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Although many studies employ subjective measures of health (i.e. parental perception of their own health) self-rated health has been found to be a strong and consistent predictor of future mortality and functional decline (Idler & Benyamini, 1997) and morbidity (Latham & Peek, 2012). Poorer self-rated health has consistently been reported by parents of children with disabilities in cross-sectional studies. Miodrag, Burke, Tanner-Smith, and Hodapp (2015) conducted a meta-analysis on the self-rated health of mothers of children with DD and CHC compared to mothers of children without disabilities using the Health Sub-domain of the Parenting Stress Index (PSI; Abidin, 1983). Of the 19 studies included in the meta-analysis, mothers of children with disabilities reported worse health than parents of typically developing children.

Parents of children with disabilities also self-report a host of somatic and general health problems such as poorer sleep quality (Gallagher, Phillips, & Carroll, 2010), headaches, gastrointestinal problems, diseases of the respiratory system, musculoskeletal system and connective tissue, endocrine, nutritional and metabolic disease (Gallagher & Hannigan, 2014; Gallagher & Whiteley, 2013; Lach et al., 2009). In a large population based study, Gallagher and Hannigan (2015) found that parents of children with DD were more likely to be obese than parents of typically developing children, putting them at risk of a range of debilitating and potentially fatal chronic health conditions such as type 2 diabetes, cardiovascular disease, and certain forms of cancer. Whilst these health issues are likely to cause distress to the parent and potential disruption to daily routine, just as concerning is the association between high perceived stress and cognitive dysfunction such as memory failure (Lovell et al., 2014). Memory failures for everyday tasks may affect the care of children who need to attend services, require medication or need to keep strict routines in place. Fatigue due to stress and poorer sleep is also likely to contribute to poorer cognitive function. Seymour, Wood, Giallo, and Jellett (2013) found that maternal fatigue influenced ineffective
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coping strategies and mediated the association between child problem behaviours and stress. These findings illustrate the vicious circle parents experience on a daily basis; stress is associated with health problems, fatigue, memory problems and ineffective coping strategies which again contribute to increased stress and poor physical health.

It is probable that poor physiological functioning is the likely underlying mechanism behind the poor health reported by caring parents (Gallagher, Phillips, Drayson, & Carroll, 2009b; Lovell et al., 2012; Ruiz-Robledillo, Andrés-García, Pérez-Blasco, González-Bono, & Moya-Albiol, 2014; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). Lovell et al. (2015) found that parents of children with autism and attention deficit hyperactivity disorder displayed elevated systemic concentrations of the proinflammatory biomarker, CRP and reported more frequent episodes of physical ill health. Proinflammatory mediators send a signal to the brain to induce behavioural symptoms of sickness such as malaise, nausea and headache and therefore may be responsible for much of these issues reported by parents. Moreover, disinhibition of the inflammatory response may put parents at greater risk for diseases such as cardiovascular disease and type 2 diabetes. Further evidence for the physiological costs of caring for a child with disabilities has been found in studies exploring antibody response to influenza (Gallagher et al., 2009a) and pneumococcal vaccinations (Gallagher et al., 2009b). In both of these studies parents caring for children with DD were found to exhibit a poorer antibody response than parents caring for typically developing children to the influenza vaccine and to the pneumococcal vaccination at both 1-month and 6-month follow-up. The inclusion of other biological markers of health associated with stress, such as blood pressure (Gallagher & Whiteley, 2013), cardiovascular response (Ruiz-Robledillo et al., 2015), electrodermal activity (Ruiz-Robledillo & Moya-Albiol, 2013) and cortisol awakening response (Lovell et al., 2015) have shown the poorer health associated
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with caring for parents of children with disabilities on all these markers. These studies provide undeniable support for the profound effects of caregiver stress on physical health.

Studies have found that poorer parental self-reported physical health is constant or increases over time, thus providing more support that parents do not manage their own health needs (Murphy et al., 2007). Eisenhower et al. (2009) explored whether developmental delay in children at age three would predict mothers perceived physical health when the child was three, four and five. When the children with delayed development were three their mothers reported poorer concurrent and later physical health, however mothers of children with developmental delay and behaviour problems reported worse self-rated physical health. However, it was child problem behaviours and also the interaction between development status and problem behaviours (but not development status itself) that predicted maternal health. Additionally, the association between child behaviour and physical health was moderated by maternal perceived stress and mediated by depressive symptoms supporting the link between stress, psychological well-being and physical health. In a longitudinal study utilising data from a Canadian large scale population based study conducted over a ten year period, the long-term implications of poorer parental physical health were supported (Brehaut et al., 2011). Parents with health problems had poorer overall self-reported health and more depressive symptoms which also persisted over the course of the study. Moreover, parental health effects increased with the increasing complexity of the child health problems. Smith and Grzywacz (2014) also suggest that poorer physical health in parents is constant over time. In a study conducted over a ten year period, there were greater declines in instrumental activities of daily living observed for parents of children with disabilities compared to parents of typically developing children.

As can be seen from the above, advances have been made in exploring the physical costs of caring on parents. Despite these advances a recent meta-analysis has called for
greater attention to be paid to the physical health of parents (Miodrag & Hodapp, 2010). In particular, they urge prioritising research on the severity of the illnesses (major /minor) experienced by parents. Therefore, studies concerned with exploring factors which may buffer physical health from stress are highly warranted and is another goal of this thesis. Here, in response to the call by Miodrag and Hodapp (2010), the focus will be on minor illnesses such as somatic illnesses (e.g., headaches, gastrointestinal problems). Moreover, these illnesses are driven by stress and are some of the most common health complaints reported by parents of children with disabilities (Gallagher & Whiteley, 2012).

Psycho-social Determinants of Psychological and Physical Health for Parents of Children with Disabilities

Child characteristics.

Factors recognised as pivotal in influencing individual psycho-social difference in parents are child behaviour problems and social support (Gallagher & Whiteley, 2013; Jellett, Wood, Giallo, & Seymour, 2015). A consensus exists that a key risk factor for parental distress are child characteristics, particularly behaviour problems. Challenging behaviours, more evident in some disorders (e.g., ASD), are problematic and distressing and as such are some of the main challenges of caring (Abbeduto et al., 2004; Gallagher & Hannigan, 2014; Lecavalier, Leone, & Wiltz, 2006; McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2006; Sipal et al., 2009). Externalising behaviours such as conduct and hyperactivity appear to drive much of the distress reported by parents (Gallagher et al., 2008; Johnston & Mash, 2001; Lovell et al., 2015). Raina et al. (2005) explored the health of a sample of parents (primarily mothers) of children with cerebral palsy and found that psychological and physical health of parents was strongly influenced by child behaviour problems. Problem behaviours
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are also associated with poorer physical health for parents. Gallagher and Whiteley (2013) found that challenging behaviour moderated the relationship between stress and physical health. Parents of children with Autism and Attention Deficit Hyperactivity Disorder (ADHD) who reported higher emotional and hyperactivity behaviour displayed atypical cortisol patterns (Lovell et al., 2015). Additionally, the parents who reported more emotional behaviours from the child also reported more commonly occurring ailments such as coughs, colds, aches, and pains. However, parental appraisal of the problem behaviour is significant; a parent who is depressed may appraise the behaviour as more problematic than a parent lower in depression. Najman et al. (2001) suggest that reports of child behaviour may be influenced by personal characteristics of the parent. They found that mothers who were less emotionally impaired reported fewer child behaviour problems than mothers who were more emotionally impaired. They suggest that depressed mothers are more sensitive to the child’s behaviour while non-disturbed mothers may be more tolerant and more likely to ignore challenging behaviour. Problem behaviours, particularly conduct or hyperactivity problems, may be associated with embarrassment, shame, avoidance and rude comments from others, feelings of powerlessness and lower subjective well-being (Francis, 2012, Green et al., 2005; Grey, 2002; Saloviita et al., 2003; Meltzer, Ford, Goodman, & Vostanis, 2011; Werner & Shulman, 2013). Given that child challenging behaviours have been consistently associated with a variety of poor health outcomes in these caring parents they will also be examined as a determinant of health and well-being in this study.

Social Support.

Alongside child challenging behaviour, one of the most significant psycho-social factors in buffering the costs of caring on parental health is social support. Social support has
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been shown to ease caregiver stress (Hodapp, Fidler, & Smith, 1998), with low levels of social support found to be the most powerful predictors of depression and anxiety in mothers of children with DD (Boyd, 2002). Inadequate social support and multiple family demands are associated with higher depression and caregiver burden (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hsiao, 2010) and lower quality of life (Ugalde, Krishnasamy, & Schofield, 2012) in these parents. Social support is also associated with parental physical health; Gallagher & Whitely (2012) found that parents with less social support had higher blood pressure. Moreover, social support has been found to be positively related to resilience and to mediate the relationship between resilience and perceived health (Ruiz-Robledillo et al., 2014). Support was also found to be inversely related to psychological distress and self-reported physical health complaints (Lovell et al., 2011). Moreover, stress has been shown to vary with social support (Dunn et al., 2001; Plant & Sanders, 2007). This is consistent with the stress buffering hypothesis which states that social support is protective under high stress conditions (Cohen, 2004). Individuals with more social support may have better health outcomes, stronger immune function and happier marriages (Bristol, 1984). Parental carers often report receiving less social support in comparison to controls (Gallagher et al., 2008) and mothers of children with more severe disabilities who reported they were not coping reported receiving even less emotional support (Leonard et al., 1993). Additionally research has indicated that parents of children with DD report decreased contact with friends (Seltzer et al., 2001), as a consequence these parents are often at risk of social isolation which may be a major contributor to negative psychological outcomes such as depression (Thoits, 1983).

The type of perceived support available may also be important, emotional and informal support has been found to be more important to parents of children with disabilities than formal supports (Benson, 2006; Boyd, 2002). Duvdevany and Abboud (2003) found that mothers who had broader informal social support reported greater well-being than those
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who used formal services and the well-being of parents using formal services was no
different to those rarely using the services. However, the precise psychosocial mechanisms
through which social support works to protect parental well-being and under which
circumstances are still poorly understood. Despite attention paid to the stress buffering role
of social support, other pathways are also likely.

One pathway through which support exerts a protective benefit is through stigma
management. Parents of children with invisible disabilities such as those with autism may be
more susceptible to perceived stigma as these parents often perceive that they are being
blamed for the children’s behaviour (Gray, 1993; Werner & Shulman, 2015). A meta-analysis
conducted by Ali, Hassiotis, Strydom, & King (2012) found support for the detrimental effect
of stigma on parental well-being and as a consequence they put forward a call for more
research on the impact of stigma on psychological well-being. Although (and as reported)
there were limited studies in the meta-analysis, those included provided support for the
association between perceived stigma and greater caregiving burden, more emotional distress
including feelings of shame, guilt and worry and reduced benefit of caregiving (Green, 2007),
less control over the children’s condition (Mak & Kwok, 2010) and the enduring negative
impact of stigma (Baxter & Cummins, 1992). A very real consequence of perceived stigma
is the avoidance of public settings and the restriction of already limited activities, which may
put the parent at risk of isolation which carries further negative consequences. Green (2003)
found after controlling for maternal and child characteristics and the daily hassles of caring
for a child with a disability that maternal perception of stigma increased distress.

Additionally, perception of stigma by the mother was found to affect children’s
interactions with other children; children of mothers with high perceived stigma interacted
less frequently with their own age peers in informal settings such as homes and
neighbourhood. Mickelson (2001) found that perceived stigma was associated with increased
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depressive symptomology, perceived lack of support and negative interactions for parents. However, the variance in perceived stigma from none to high levels of perceived stigma is stressed and the author points out how society influences perceptions of stigma. Therefore, in response to the call by Ali et al. (2012) and also given the lack of attention to factors which protect parental well-being against the impact of perceived stigma, a focus in this thesis will be on protective factors which lessen the impact of stigma on parental well-being. Moreover, given that lack of support is associated with increased stigma in these parents, it could be that higher levels of social support may buffer against the role of stigma on the health of these parental carers. Thus, attending to the psychosocial pathways through which social support exerts its protective influence will also be a goal of this thesis.

Other Contributing Psychosocial Factors to Parental Well-Being

While factors such as social support and child behavioural characteristics have garnered the most research attention in relation to parental outcomes there is no doubt that more distal factors such as personal psychological resources are equally important. In fact, a reciprocal relationship is likely to exist between parental personality factors and these risk and protective factors (Gill & Harris, 1991) for example, factors such as mastery and self-esteem will likely influence appraisal of child behaviour and also number and quality of friendships - which will subsequently be associated with social support. Thus, these personal resources may also serve as other explanatory pathways behind the social support-health relationships in this caring context. The significance of psychological resources, such as self-esteem and mastery, as the linchpin in successful adaptation has been noted in other family and stress contexts and may be relevant here. For example, the fundamental importance of the primary carer’s psychological resources in the parental child dyad is discussed by Belsky (1984) in the Determinants of Parental Functioning. He suggests that when two of the three
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determinants of parenting (personality/psychological well-being of the parent, characteristics of the child and contextual sources of stress and support) are at risk, optimal functioning can still occur if the personal psychological resources of the parent are positive. The psychological resources of the parent may also be responsible for driving the establishment of beneficial resources both within the family (e.g., appraisal of the stressor, coping styles, cohesion) and externally (e.g., interventions, social support, health of family) and may largely mediate successful family adaptation. Belsky (1984) proposes that personal psychological resources are important in the quality of the support received due to choice of spouse, friends and job, all of which may positively impact psychological well-being. The reciprocal nature of psychological well-being i.e. positive psychological well-being influencing lifestyle choices that further reinforce well-being provides more evidence for the cruciality of optimising psychological functioning for the parental carer.

Pearlin and Schooler (1978) suggest that personal psychological resources such as self-esteem, mastery and self-denigration were more helpful to family members dealing with caregiving strains over which they had no direct control. They propose it is what you think of what you do that matters more than what you actually do (i.e. coping strategies) in stressful situations. Similarly, Perry (2004, p7) suggests that the personal resources of the individual is a domain “most ripe for research efforts aimed at discovering the particular internal resources, beliefs and coping abilities that are most effective in reducing stress”. Although coping resources such as personality measures (Baker, Blacher, & Olsson, 2005; Glidden et al., 2006; Olsson & Hwang, 2002), parental cognitions (Hassall, Rose, & McDonald, 2005), and parenting efficacy (Woodman & Hauser-Cram, 2013) have been explored in parental health research (Morgan & Baron, 2011; Paczkowski & Baker, 2008), the underlying pathway to the successful maintenance of beneficial personal resources, in particular mastery
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and self-esteem, which may have the potential to buffer the effects of caregiver burden of the health of parents (Jones & Passey, 2004) is yet to be explored.

Mastery.

Mastery, the perception that one has control over life obstacles (Pearlin & Schooler, 1978), has been implicated as a beneficial resource for health outcomes in stressful contexts. The association between mastery and stress can be observed in the Transactional Model of Stress and Coping (Lazarus & Folkman, 1987) whereby an individual who appraises a stressor as controllable is theoretically believed to display an attenuated response to stressors (Lazarus & Folkman, 1984). This attenuated response to stressors is likely to affect health in a positive manner. In fact, mastery has been found to be associated with better psychological health (Haidt & Rodin, 1999; Raina et al., 2005; Singer & Farkas, 1989), as well as better caregiver psychological and physical health (Roepke et al., 2008), including lower incidence of coronary heart disease (Lundgren, Garvin, Jonasson, Andersson, & Kristenson, 2014), better self-rated health, better functional status, and lower mortality (Seeman & Lewis, 1995) in caregivers.

In terms of underlying pathways, Paczkowski and Baker (2007) explored the association between mastery, child problem behaviours, and parenting practises for parents of children with DD. Whether parents reacted to their childrens negative emotions with either supportive parenting practise (e.g., emotion or problem focused reactions and expressive encouragement) or non-supportive parenting practise (e.g., minimization, punitive or distress reactions) were examined. They found that mastery was inversely related to child problem behaviours and although low levels of mastery were associated with non-supportive parenting it was not associated with supportive parenting. Higher levels of non-supportive parenting were associated with child behaviour problems however supportive parenting did not predict
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fewer behaviour problems. Moreover, they found that parenting practises mediated the association between mastery and problem behaviour. The benefit of mastery over time was reported in a population based longitudinal study conducted over a ten year period (Smith & Grzywacz, 2014). They explored the protective role of social support and mastery on the health outcomes of parents of children with a chronic disease, disability or emotional problems over a ten year period. They found that parents had greater increases in depressive symptoms over time and also greater declines in instrumental activities of daily living however mastery was negatively related to depressive symptoms and also was a robust predictor of all health outcomes over time.

There is no doubt to the benefit of a high sense of mastery for health however mastery is often posited as a fixed personality attribute relatively unaffected by events. Conversely Skaff, Pearlin and Mullen (1996) propose that mastery is not fixed but responsive to the conditions of the individuals life and will increase or decrease in a way that is reflective of the nature of these conditions. The impact of transitions on the careers of Alzheimer's caregivers (456 spouses and adult children caring for a family member with Alzheimer's disease) on their sense of mastery was examined over time. They found that for those who continue to care for their relative, mastery declines; for those who place their relative in a care facility, mastery remains unchanged; and for those who experience the death of their relative, mastery increases. A sense-of-self was found to be more important than caregiver stress for levels of mastery, over time an increase in a loss of self-predicted a decline in mastery. This may be very pertinent to parents of children with disabilities. Beresford, Rabiee, and Sloper (2007) suggest that personal identity was one of the main concerns for parents. They found that parents reported they had ‘lost’ aspects of their personal identity, with the role of parent/carer dominating how they felt about themselves and how other people viewed them. Work, interests, and personal relationships were the three areas parents
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reported to play a key role in their sense of identity and which they wanted to have time or support to allow them to pursue. However the underlying pathway to how mastery is associated with better parental outcomes and also how mastery interacts with other risk and protective factors is unclear. A better understanding of these synergistic relationships is a goal of this thesis.

Self-esteem.

Self-esteem may also be associated with a sense-of-self. Self-esteem is the global evaluation one has of one’s own self-worth (see Rosenberg, 1986) and has been found to play an important role in parental health outcomes. Higher self-esteem in parents of children with disabilities has been found to predict greater resilience, better psychological health, and better physical health (Bekhet et al., 2012; Raina et al., 2005). Lovell et al. (2011) found that for parents of children with ADHD, psychological distress and physical health complaints were inversely related to scores on all support subscales: tangible, belonging, self-esteem and appraisal. Furthermore, they found a positive association between magnitude of the cortisol awakening response (CAR) and self-esteem, providing evidence for a link between social support, self-esteem and health. Marcussen, Ritter, & Safron (2004) posit that self-esteem is a coping resource that buffers the impact of stress on psychological well-being, therefore identifying circumstances that facilitate positive self-esteem would be extremely advantageous for parents. Of interest is the pathway to how self-esteem protects parental health and also the interaction with other factors, such as stress and social support. Additionally, whether self-esteem is only protective under certain conditions i.e. low stress and also whether self-esteem varies with levels of social support. Previous studies have not looked at the conditions under which self-esteem operates or synergistic relationships with other more established risk and protective factors.
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Role Identities

Wickrama, Conger, Lorenz, & Matthews (1995) propose that beneficial resources such as self-esteem and mastery may be influenced by identity processes, such as role identities. They suggest that increasing psychological well-being through successful enactment of a salient role identity may be the pathway to increasing health outcomes. This is particularly relevant for parental carers given the wide range of health costs already outlined. Role identity theory (Burke & Stets, 2009) is a useful social psychological framework in examining the protective function of embracing role identities and may perhaps provide another level of analysis in predicting some variance in health outcomes. Role identities are social roles in which individuals internalise the meanings of the role that applies to them. Further, given that the Double ABCX model of caregiver adaption has been criticised for being underspecified regarding the relationships between concepts (Jones & Passey, 2004), role identity theory is one way of facilitating a better understanding of how these concepts relate to each other. For example, these roles provide meanings that individuals attribute to their role as a group member, role holder, or person (Stets & Burke, 2003) defining who one is in the context of a given role (e.g., mother, caregiver; Burke & Stets, 2009). Therefore, our role identity is our perception of who and how we are in a particular role, i.e., how we see ourselves being and acting. Role identities can “provide structure, organization, and meaning to selves and to situations” (Burke & Stets, 2009, pp113) and can help guide behaviour as societal norms and expectations are internalised. Successfully managing the behavioural expectations associated with a role should than have a positive impact on self-esteem, mastery and subsequent well-being. When an individual endorses a particular role identity they are then motivated to maintain consistency between their identity and their behaviour (Stets & Burke, 2003) additionally others expectations and
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appraisals of us in the role should support our role identity particularly when they confirm our view of ourselves.

It is through carrying out a role that role identities are realized and validated (Callero, 1985). Despite this, many familial carers although enacting the role of a carer do not recognise themselves as such, many believing that they are fulfilling a normal and expected familial role (Kutner, 2001; O’ Conner, 2007). Moreover, Ugalde et al. (2012) suggest that without outside influence (such as being given a description of what a carer does) many carers do not identify as such and critically, identifying as a carer has many positive benefits such as accessing supports. The strength of carer role identity is likely to be related to a variety of other behavioural outcomes such as more time caring for a child, sacrificing of other roles and involvement in advocacy or carer associations. Furthermore, strength of carer role identity is possibly associated with variables such as role self-efficacy, self-esteem and mastery, which may impact self-regulation and lower levels of parental stress (Burke & Stets, 2009; Oyserman, Bybee, Terry, & Hart-Johnson, 2004), as such may influence parental health. Indeed, research from social gerontology has found that identifying as a carer appears to facilitate better psychological health. Savundranayagam and Montgomery (2010) explored role identity processes and psychological distress in spousal carers of Alzheimer sufferers and found that spouses who adjusted their spousal role identities to include meanings (e.g., caring behaviours) from their carer role identity reported better psychological adjustment. Although the pathway from an identity as a spouse or family member (i.e. daughter/ son) to a carer is substantially different to that of a parent where the parent and carer roles are bound - an identity perspective may offer an account for some of the variance in outcomes in parents of children with disabilities. For example, if a parent holds a role identity in which they feel competent, such as that of a parent, an advocate for children with disabilities, or an employee,
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this may boost self-esteem and well-being which may affect mastery and coping in the caring role.

Callero (1985) suggests that self-esteem rests on successful evaluation of the self therefore the definitions that someone holds linked to their important role identities are crucial. When an individual is successful in enacting an important role identity there should be a corresponding increase in self-esteem. Promoting self-esteem in this way should allow the individual to feel competent and masterful and as a consequence should increase psychological well-being. In fact, the benefit of having a strong identity in a domain that allows for successful evaluation of the self can be seen in studies which found that employed caregivers often report better emotional adjustment (Youngmee, Baker, Spillers, & Wellisch, 2005). Olsson and Hwang (2006) report a positive relation between involvement in paid work and well-being for both mothers and fathers of children with DD. They also found no difference in well-being between mothers who worked full-time and mothers who worked part-time, supporting the benefit of employment to parental carers. Additionally mothers with higher career aspirations report more psychological distress when they are forced to give up work to care (Scott, 2010). Gerstein, Crnic, Blacher and Baker (2009) suggest that the distress experienced by mothers of children with disabilities may be due not only to the fact that they take on a larger part of the extra care and practical work but they more often give up their jobs and feel unable to pursue their own interests. Moreover, if self-competence is tied to the parenting role they may be more vulnerable to stress and difficulties which arise in the parenting domain. Together this suggests that role identities are important for parental health either on its own or through interaction with other psychosocial factors.

Extending on this line of enquiry, research has also found that those who have fewer role identities to be more susceptible to stress, this is where the benefits of role accumulation and multiple identities can be seen (Thoits, 1983). Having a choice of roles may offer the
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individual the opportunity to choose to engage in another role that is less demanding, this may also provide a distraction when aspects of a highly important role identity become stressful. Thoits (2003, 2012) suggests that engaging in voluntary roles such as sports or volunteering may enhance psychological well-being; these roles may be less demanding and may in promoting role self-efficacy may also boost self-esteem. Restriction in social activities due to tasks involved with caring was found to most strongly affect parental stress (Cramm & Nieboer, 2011). Therefore, encouraging and assisting parents to continue in their social roles may be beneficial in alleviating distress. Identity theorists suggest the more roles a person occupies that are meaningful and give purpose to their life, the better their psychological well-being (Thoits, 2003). Parental carers may choose, for example, to become involved with support groups, take courses, join sports groups or school parental associations to add to their role identities. Likewise, Eisenhower et al. (2009) suggest that social roles beyond parenting should be explored as they may have the potential to moderate the pathway between child-related stressors and maternal health.

Although there are benefits of multiple identities, role conflict and role balance theorists (e.g., Marks & MacDermid, 1996) suggest that someone attempting to juggle too many role identities will struggle to achieve role balance and will experience role conflict. This may be particularly relevant for parental caregivers where balancing the demands of childcare may ultimately take priority and supersede other role identities. However, Skaff, Pearlin and Mullen (1996) found that for familial carers of Alzheimer sufferers, it was not feelings of being worn out and overworked that was associated with higher stress and lowered levels of mastery as was expected but a sense-of-self. A consequence of balancing the demands associated with caregiving is that there may be a loss of roles, such as employment, education and social activities, which may be important to the self-concept. Support for this can be seen in mothers who are highly educated and have high career
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aspirations, when the self-concept is highly connected to their career identity and they are forced to give up work to care, they report more psychological distress than mothers whose self-concept is not connected to their career identity (Scott, 2010). Despite, the obvious difficulties in balancing multiple roles, evidence would suggest the benefits of holding multiple identities outweigh the loss of identities. A loss of identities may lead to social isolation, while an individual with more role identities may be more socially integrated; however there may be a limit to the number of role identities that one can hold that are beneficial (Thoits, 1983). Eisenhower and Blacher (2006) found evidence for a role shortage effect rather than role enhancement for mothers of young adults (16-26) with DD. There was no additional benefit of having three rather than two roles (e.g., employment, spouse) but mothers did experience well-being risk when they had a shortage of roles. Brook, Garcia, and Fleming (2008) suggest that it is the importance of the identities and the relationship between them that will have an effect on well-being. When identities are important, having more rather that few will lead to better psychological well-being if the identities are not in conflict with each other, with less important identities neither the number of identities held or harmony between these identities will affect well-being.

Identity and mental health researchers (e.g., Burke, 1991; Thoits, 1991; Large & Marcussen, 2000) emphasise that the key to understanding the extent to which stress affects an individual is in the meanings attached to the role identity. Thus, a role identity perspective looks to how identity processes such as identity importance, performance, multiple identities and role balance may influence the impact stress has on health outcomes (Wickrama et al., 1995). The influence of role identity processes on health outcomes has yet to be examined in parental carers, in particular the protective aspect of multiple roles and how they may work in tandem with other psychosocial factors. Taken together, incorporating this perspective is one way in which role identity theory may help clarify how the concepts of coping and role
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changes influence adaptive process as proposed by the Double ABCX model. Finally, roles identities have not been examined in this context and an exploration of role identities and particularly the underlying constructs (i.e. mastery and self-esteem) may offer another level of analysis in examining the differential susceptibility to the demands of caring and provide more of an understanding of the variability in parental health outcomes.

The Present Thesis

In summary, although research so far indicates that much of the variation in outcomes is accounted for by a confluence of factors including risk (e.g., poverty, lack of resources, single parent) and protective factors (e.g., availability of resources, strong marriage, sufficient income; Olsson et al., 2008), a plethora of research supports child characteristics, particularly behaviour problems, and social support as key risk and protective factors underlying stress appraisal by parents. However, identifying other potential buffers is a main concern for researchers and is a primary goal of this thesis. Pottie, Cohen, & Ingram (2009, p.419) suggest that rather than identifying factors predictive of psychological distress, “factors that assuage the effect of parenting stress on psychological distress, as well as factors that enhance positive affective states or well-being should be explored”. However, the underlying psychosocial pathway to the successful maintenance of some of these beneficial protective factors (such as self-esteem and mastery), which may mediate caregiver distress is yet to be explored in parents caring for children with disabilities. An understanding of the role of these protective factors and particularly how they operate to protect parental health would not only add significantly to the existing literature and extend theoretical knowledge, but also better inform future psychosocial interventions for these caring families as a more accurate picture of the factors contributing to well-being could be used as targets for manipulation.

Based on the above literature review, the present thesis aims to first extend on this existing body of knowledge by conducting a cross-sectional and longitudinal study to
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examine predictors of psychological and physical well-being. Second, to develop a new understanding of how other, relatively unexplored psychosocial factors, may also be important synergistic determinants of parental well-being. These studies gave rise to four distinct research papers which comprise the main body of the thesis. Two of these papers have been published in peer-reviewed journals and a further two have been submitted for peer review.

The main hypotheses as contained in each paper were:

1. In paper one, given the call for research to examine the predictors of minor physical illnesses (Miodrog & Hopper, 2010), the synergistic relationships between psychosocial factors and physical health was explored. It was hypothesised first, that compared to age-and gender matched control parents, parents caring for children with a disability would report poorer self-rated physical health. Second, that mastery and social support would be positively associated with better physical health whereas behaviour problems and perceived stress would be associated with poorer physical health in parents of children with a disability. Third, that the relationship between mastery and physical health would be mediated by stress. Finally, the association between perceived stress and physical health in these caring parents would be moderated by social support.

2. In paper two, extending previous studies that examined the association between psychosocial factors and depression individually, but examining the synergistic relationship between stigma, self-esteem and social support, as predictors of depressive symptomatology in parents of children with disabilities.
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It was hypothesised first, that compared to age and gender matched controls, parents caring for children with disabilities would report higher depressive symptomology, higher stigma, lower social support and lower self-esteem. Second, that self-esteem and social support would be negatively associated with depressive symptomology whereas child behaviour problems would be positively associated with perceived caregiver stigma and further both would be positively associated with depressive symptomology in parents of children with disabilities. Third, that caregiver identity would be associated with higher perceived stigma and lower self-esteem. Fourth, that the relationship between perceived stigma and depressive symptomology would be mediated by self-esteem. Finally, we aimed to test whether the association between perceived caregiver stigma and depressive symptomology through self-esteem would vary as a function of social support.

3. In the third paper, psychosocial predictors of psychological well-being in parents caring for children with disabilities over time were explored. It was hypothesised first, that there would be cross sectional association between child behaviour, perceived stress and poorer psychological well-being. Moreover that social support, participation in roles outside caring, self-esteem and mastery would be associated with better psychological well-being. Second, that self-esteem, mastery and participation in roles would predict some of the variance in psychological well-being for parents of children with disabilities.
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4. Finally, in the fourth and final paper the aim was to explore associations between role factors (i.e. multiple identities, role identity content [importance/ performance], and role balance), established risk and protective factors, and psychological well-being in parents of children with disabilities. Extending on past analysis and integrating findings from the three previous papers and role factors to understand how these factors may combine to affect parental psychological health outcomes. The first hypothesis was that depressive symptomology will be positively associated with stress and child problem behaviour and negatively associated with social support, mastery and self-esteem. Second, that parents who identify as a carer are more likely to be involved in carer related activities (i.e. support groups, advocacy) and will report higher perceived support and less depressive symptomology. Third, that performance in important role identities will be associated with depressive symptomology, mastery and self-esteem. And last, that role factors will predict additional variance in psychological well-being beyond established risk and protective factors (i.e., child behaviour, support).
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CHAPTER THREE

Paper One

Social support and mastery influence the association between stress and poor physical health in parents caring for children with developmental disabilities.
Abstract

To date, much of the research linking the stress of caring for children with developmental disabilities (e.g., Autism & Down syndrome) with parental health outcomes have tended to concentrate on mental health with less attention paid to the physical health consequences. Thus, this study sought to explore the psychosocial predictors of poor physical health in these caring parents. One hundred and sixty-seven parents (109 caregivers and 58 control parents) completed measures of stress, child problem behaviours, social support, mastery and physical health. Parents of children with developmental disabilities had poorer physical health compared to control parents. Stress and mastery, but not social support and problem behaviours, were significant predictors of poor physical health within caring parents for children with developmental disabilities. However, the association between mastery and physical health was mediated by perceived stress such that those parents who were higher on mastery reported less stress and better physical health; furthermore, the association between stress and physical health was moderated by social support; those parents high on social support and low in stress had better physical health. These results indicate that the paths between psychosocial factors and poor physical health in the caring parents are working synergistically rather than in isolation. They also underscore the importance of providing multi-component interventions that offer a variety of psychosocial resources to meet the precise needs of the parents.

Keywords: Parents, developmental disability, physical health, mastery, social support, stress
Introduction

A wealth of research attests to the negative psychological impact of caring for a child with developmental disability (e.g., Autism, Down syndrome, and Fragile X) on parents. Although some parents cope well with the demands and challenges of caring for a child with a developmental disability (DD; Ollson & Hwang, 2008; Scorgie, Wilgosh, & McDonald, 1998), others do not, and as a consequence are more likely to experience outcomes such as distress (Gallagher & Hannigan, 2014; Thurston et al., 2011), anxiety, low self-esteem, depression (Ollson & Hwang, 2008), poorer general emotional health, and pessimism about the future. More recently a call for researchers to examine the physical health of these caring parents has been made (Miodrag & Hodapp, 2010), which seems particularly pertinent given likely economic costs of illness in carers. Consequently, research efforts have begun to explore the physical health of caring parents.

In fact, research has found that relative to age- and gender matched control parents, parents of children with DD have poorer physical health (e.g., poor sleep, greater risk of hypertension, arthritis, increased headaches and higher rates of infection; Gallagher & Whitley, 2013; Lovell, Moss, & Wetherall, 2012; Resch, Benz,& Elliott, 2012). Moreover, poor physiologically functioning is the likely underlying mechanism behind the poor health in caring parents (Gallagher, Phillips, Drayson, & Carroll, 2009; Lovell et al., 2012; Ruiz-Robledillo, Andrés-García, Pérez-Blasco, González-Bono, & Moya-Albiol, 2014; Seltzer, Greenbergn Floyd, Pettee, & Hong, 2001). Although the two key factors that drive this association, social support and child problem behaviours, have received the bulk of attention from researchers, less attention is paid to coping styles. Further, research has established that physical health in these caring parents was best explained not by single psychological factors but more so by the interaction of two predictors variables (Gallagher & Whiteley, 2013).
that case, child problem behaviours exacerbated perceptions of stress to negatively impact physical health. Taking a piecemeal approach rather than testing integrated models has been criticised (Matthews & Gallo, 2011), indicating that this type of synergistic research is clearly warranted.

Child behaviour issues, particularly externalizing behaviours such as hyperactivity and conduct problems have consistently been shown to explain a significant proportion of the variance in parental distress and poor physical health in caring parents (Baker, Seltzer, & Greenebrg, 2012; Hodapp, Fidler, & Smith, 1998; Blacher & McIntyre, 2006; Floyd & Gallagher, 1997; Gallagher et al., 2009; Hastings, Daley, Burns, & Beck, 2006). Problematic behaviours were found to moderate the association between stress and physical health (Gallagher & Whiteley, 2013), such that parents who reported more problem behaviours also reported more perceived stress and poorer health. However, stress in parents has also been shown to vary with social support (Bailey, Wolfe, & Wolfe, 1994; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001); those who report more social support tend to report less stress. Although social support is vital for physical health (for review see Uchino, 2009) and has been shown to have a direct effect on blood pressure and immune function in parents (Gallagher & Whitely, 2012; Lovell et al., 2012; Ruiz-Robledillo et al., 2014), one pathway through which social support exerts its effect on health is through stress buffering.

The transactional model of stress (Lazarus & Folkman, 1984) suggests internal and external resources are influential in determining an individual’s stress appraisals. Social support is a key external resource that has been found to influence stress appraisals (see Uchino, 2009). According to the stress buffering hypothesis (Cohen & Wills, 1985) social support, particularly perceived support, impacts health outcomes through its influence on the appraisal of the stressful situation. Those with a high level of perceived social support are less likely to appraise a situation as stressful as those with low social support. Therefore,
parents with high levels of perceived social support are more likely to report fewer negative reactions to parenting stress than parents with low social support. To our knowledge, no study has examined the buffering role of social support on stress appraisals in this context, although positive appraisals were associated with lower depression and lower perceptions of stress among parents (Trute, Benzies, Worthington, Reddon, & Moore, 2010), implying that there may be a key role for the influence of social support in stress appraisals in this context. Thus, given that social support is inversely related to psychological issues such as depression and anxiety and is expected to “buffer” parents from stress through influencing how they perceive the stressful situation, it could be that social support influences physical health in these caring parents through its impact on perceptions of stress.

In terms of the transactional model of stress, individuals appraising stressors as controllable are theoretically believed to display an attenuated response to stressors (Lazarus & Folkman, 1984). And consistent with this, mastery or the belief that one has control over life’s obstacles has been associated with better psychological health (Haidt & Rodin, 1999; Singer & Farkas, 1989), as well as better caregiver physical health (Roepke et al., 2008, including lower incidence of coronary heart disease (Lundgren, Garvin, Jonasson, Andersson, & Kristenson, 2014), better self-rated health, better functional status, and lower mortality (Seeman & Lewis, 1995). However, whether or not mastery has similar protective effects against poor physical health in these caring parents has yet to be investigated. Further, although the influence of mastery on levels of problem behaviour and psychological health in parents of children with DD has been examined (Paczkowski & Baker, 2007; Raina et al., 2004) the interactive pathways between perceived stress, social support, mastery and physical health have not been tested. In fact, to our knowledge, this is the first study to test these interactive pathways and it is in line with a recent call for researchers in paediatric psychology to use contemporary statistical techniques to test interactive effects (Karazsia,
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Berlin, Armstrong, Janicke, & Darling, 2013). We hypothesise that control of stressful situations will consequently enable parents to feel more confident and masterful hence protecting their health (Hastings et al., 2006). Thus, it could be that the association between mastery and physical health may be explained again by its impact on parental stress appraisals.

So to develop an understanding we take these variables mastery, stress appraisal, social support and test their effects interactively for those caring for a child with DD. Based on the evidence, it is hypothesised first, that compared to age-and gender matched control parents, parents caring for children with DD will report poorer physical health. Second, that mastery and social support will be positively associated with better physical health whereas behaviour problems and perceived stress will be associated with poorer physical health in parents of children with DD. Third, that the relationship between mastery and physical health will be mediated by stress. Finally, the association between perceived stress and physical health in these caring parents will be moderated by social support.

Method

Participants, Design and Procedure

This study had a cross sectional design with two sets of parents recruited and variables measured across two cohorts. Parents were recruited through word of mouth and University survey recruitment lists via e-mail. Although the survey questionnaire was accessible both online, via survey software (survey monkey) hard copies were made available, most parents completed the questionnaire online (99.1 %) which has been found to be a robust method for data collection (Deutskens, de Ruyter, & Wetzels, 2006). Parents of children with DD were recruited through invitation letters distributed by local schools for
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children with special needs and by organisations supporting parents of children with developmental disabilities. Invitation letters were also placed by such organisations on their social media pages (e.g., Facebook). Inclusion criteria for parents were providing care to a child with a developmental disability under the age of eighteen who lived at home. Forty-five per cent of parents reported caring for children with autistic spectrum disorder, 10%, with Down’s syndrome and 45% with mixed disabilities. In total 109 parents of children with disabilities and 58 control parents completed the questionnaire. A power calculation (probability level of 0.05, effect size of 0.25 and power of 80%) specified a sample size of 128. The study was approved by the relevant University Research Ethics Committee and all participants gave informed consent.

Measures

Socio demographic characteristics.

Respondents provided information on their age, gender, marital status, education level, ethnicity, number of children under the age of 18 in the household, age of the child and if the child had a disability. Socio-economic status was measured using The Registrar General’s social classification (Office of Censuses and Surveys, 1972). Participants were asked to specify their occupation, which was scored, 1, professional (e.g., physician), 2, managerial (e.g., director), 3, non-manual/clerical (e.g., secretary), 4, skilled manual (e.g., carpenter), 5, semi-skilled manual (e.g., bus driver), 6, unskilled manual (e.g., labourer). A simple categorical scoring of manual (4, 5, 6) vs. non-manual (1, 2, 3) was created. This measure has been used in previous caregiver research (Gallagher & Whitleley, 2013).
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Psychological Stress.

The 4-item Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983) was used to measure psychological stress over the previous month. This scale, used previously in caregiver research (Gallagher, Phillips, and Carroll, 2010; Vedhara et al., 2002) measures how stressful individuals perceive situations they have experienced over the last month. Scale responses range from 0, never, to 4, very often, and include two reverse scored items, with higher scores indicating greater perceived stress. Items in the scale include ‘In the past month, how often have you felt able to control the important things in your life?’ and ‘In the past month, how often have you felt things were going your way?’ The scale has shown high internal consistency reliability (Cronbach’s $\alpha = .88$) in previous research (Gallagher & Whiteley, 2013). In the present study a high internal consistency reliability of $\alpha = .80$ was observed.

Mastery.

The Personal Mastery Scale (Pearlin & Schooler, 1978) is a 7-item scale that measures the extent to which an individual feels control over life outcomes. Items include “I often feel helpless in dealing with the problems of life” and “What happens to me in the future mostly depends on me”. Items are scored on a scale from 1 (“strongly agree”) to 4 (“strongly disagree”), and negatively worded items are reversed scored. Higher scores indicate higher mastery. This scale is one of the most widely used measures in health research and a high internal reliability has been found in previous caregiver research (Cronbach’s $\alpha = 0.73$; Sherwood et al., 2007). In the present study a good Cronbach $\alpha = .82$ was observed.
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Social support.

Social support was assessed with the 12-item Support functions scale (Dunst, Jenkins, & Trivette, 1984). Parents were asked to rate sources of support available to them on a 5-point Likert scale ranging from 1 (“never”) to 5 (“quite often”). Sources of support available include practical support (e.g., someone to help take care of your child) and emotional support (e.g., someone to talk about things that worry you). Both the total score and the total of the subscales were used for analysis with higher scores indicating more social support. Others have used this scale previously (Gallagher et al., 2009; Gallagher & Whitely, 2012). A high internal consistency reliability was shown in the present study for the total scale $\alpha = .91$, emotional support subscale $\alpha = .85$ and practical support subscale $\alpha = .85$.

Child challenging behaviours.

The Strengths and Difficulties questionnaire (SDQ: Goodman, 1997) was used to measure child challenging behaviours. However, only two of the subscales measuring conduct disorder (e.g., ‘often argumentative with adults’; 5-item) and hyperactivity (e.g., easily distracted, concentration wanders; 5-item) were chosen as previous research has indicated that these challenging behaviours are one of the main sources of stress in these parents (Sipal, Schuengel, Voorman, Van Eck, & Becher, 2010). The questionnaire has been used extensively in research with children with DD and their parents (e.g., Beck, Daley, Hastings, & Stevenson, 2004; Hastings et al., 2006). Parents self-report whether a behaviour is somewhat true (scored 0), true (scored 1) or certainly true (scored 2) of their child, some items are reversed scored (e.g., generally obedient, usually does what adults request). Higher scores indicated more problem behaviour. The scale has been shown to be reliable (Cronbach’s $\alpha = .78$) and effective at identifying challenging behavioural problems in
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children (Goodman & Scott, 1999). Internal consistency reliability in this study was adequate Cronbach $\alpha$ 0.78, reliability for the subscales were also adequate; hyperactivity ($\alpha$ 0.68) and conduct ($\alpha$ 0.79).

Physical health.

Self-report parental physical health was assessed with the Physical Health Questionnaire (PHQ; Schat, Kelloway, & Desmarais, 2005). This brief 14-item self-report scale of somatic symptoms including sleep disturbances (Have you woken up during the night), headaches (Have you experienced headaches), gastrointestinal problems (have you suffered from an upset stomach), and respiratory infections (have you had respiratory infections more severe than minor colds that “laid you low”). Parents are asked to rate how often they have experienced these symptoms during the last year, from 1 (not at all) to 7 (all of the time). A higher score is an indication of poorer physical health. This scale has been used in parental carer research previously (Gallagher & Whiteley, 2013) and has shown good internal consistency. In the current study a Cronbach $\alpha$ .84 was obtained, values for subscales were; sleep disturbance ($\alpha$.04), headaches ($\alpha$.92), gastrointestinal problems ($\alpha$.88) and respiratory infections episodes ($\alpha$.80). A single item question which asked parents ‘Compared to others of your age and sex, how would rate your general health?’ was included, the response was either, excellent (scored 5), above average (scored 4), average (scored 3), below average (scored 2) or very poor (scored 1).

Statistical Analyses.

Initial analyses of group differences were by Chi-square, t-Test, and univariate (ANOVA) with partial eta – squared ($\eta^2_p$) as the measure of effect size. Bivariate correlation analyses was used to determine whether any demographic variables, caregiver characteristics,
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mastery, perceived stress or social support were related to physical health in the caregiver group. Subsequent analyses focused on within group analyses, i.e., psychosocial predictors of poor physical health in parents caring for children with disabilities. Indirect effects analysis was conducted using the PROCESS macro created by Preacher and Hayes (2012) in SPSS. The bootstrap procedure was used to further evaluate the significance of the mediator. We based the estimate of the indirect effect by running 1,000 bootstrap iterations of computed samples and used a 95% confidence interval (CI). A mediation model (Model 4) tested the mediating effect of perceived stress on the relationship between mastery and PHQ. A moderation model (Model 1) was used to test if the association between perceived stress and physical health was moderated by perceived support.

Results

Parental Socio-Demographic Characteristics, Psychosocial Factors and Physical Health

In terms of socio-demographics, the majority of participants were female (91%; mean age = 40.1, SD = 7.2 years), white (97%) and married (72%) with the remainder of the sample separated/ divorced (13%), single (14 %), or widowed (1%). Parents had an average of two children and the median age of the children in the control group was slightly lower however number of children in family and age of child were not related to outcome variables. The two parent groups matched on socio economic status U = 2684, \( z = -0.824, p=0.41 \), the median income level of parents was in the €20,000 - €40,000 bracket. Other pertinent characteristics of the parental group are presented in Table 1. As can be seen the two parental groups did not differ significantly on age, gender and marital status.

Parents of children with DD reported higher perceived stress, lower mastery, less social support and more physical health problems than control parents (see Table 1).
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Moreover, the effect sizes (partial eta-squares of $\eta^2_p$, .48, .46, .38, and .47, respectively) signify large and medium significant differences. Analysis of the PHQ subscales indicated significant differences between the parental groups on all 4 subscales; sleep disturbance, $U = 2384, z = 2.63, p < .01$, headaches, $U = 1517, z = 5.54, p < .000$, gastrointestinal $U = 2141, z = 3.43, p < .001$ and respiratory infections, $U = 1968, z = 4.03, p < .000$. Parents of children with DD reported their health as worse across all domains. Moreover, parents of children with DD rated their health as average compared to control parents who rated their health as above average.

Associations between Predictor Variables and Physical Health in Parents Caring for Children with Developmental Disabilities

Preliminary analyses were conducted to check for associations between caregiver demographics and physical health. Only gender was related to physical health ($p < .05$), with females reporting worse overall health, $U = 257, z = -2.20, p < .05$, than males. Perceived stress was positively correlated with physical health and mastery was negatively correlated with physical health suggesting that parents who are high on perceived stress and lower on mastery report worse physical health (See Table 2). Regarding the PHQ subscales, mastery was associated with all four health subscales but more so with sleep disturbance ($r = -.287; p < .01$); perceived stress was associated with gastrointestinal problems ($r = .310; p < .01$). Surprisingly, behaviour problems and social support were not associated with physical health. But social support was significantly associated with mastery and perceived stress, with mastery associated with higher perceived emotional support (see Table 2).
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Table 1. Demographic, psychosocial and physical health characteristics of parents caring for children with intellectual disabilities (caregivers) and control parents

<table>
<thead>
<tr>
<th></th>
<th>Caregivers (N = 109)</th>
<th>Control (N = 58)</th>
<th>Test of difference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender (Female)</strong></td>
<td>100 (92 %)</td>
<td>52 (90 %)</td>
<td>$X^2(1,167)= .202, p &gt; .05$</td>
</tr>
<tr>
<td>Median age (years)(IQR)</td>
<td>41 (11)</td>
<td>39 (9)</td>
<td>$U = 2.737, z = -1.259, p &gt; .05$</td>
</tr>
<tr>
<td>Median age of main care recipient (years)</td>
<td>(10, n = 167)</td>
<td>(8, n = 71)</td>
<td>$U= 4.689, z = -2.556, p &lt; .05.$</td>
</tr>
<tr>
<td>Median Physical Health Score (IQR)</td>
<td>53 (20)</td>
<td>40 (17)</td>
<td>$U= 1567.5, z = -5.360, p &lt; .000$</td>
</tr>
<tr>
<td>Mean PSS score (IQR)</td>
<td>9.00 (4)</td>
<td>5.50 (4)</td>
<td>$U = 1317.5, z = -6.226, p &lt; .000$</td>
</tr>
<tr>
<td>Median Mastery score (IQR)</td>
<td>17.00 (4)</td>
<td>21.00 (4)</td>
<td>$U = 4954.5, z = 6.051, p &lt; .000$</td>
</tr>
<tr>
<td>Mean SDQ (parental carers only) (SD)</td>
<td>12.08 (4.36)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median Support Functions Scale (Total) (IQR)</td>
<td>31.00 (11)</td>
<td>43.00 (15)</td>
<td>$U = 4622.5, z = 4.916, p &lt; .000$</td>
</tr>
<tr>
<td>Median Emotional subscale (SF) (IQR)</td>
<td>19.00 (7)</td>
<td>24.00 (7)</td>
<td>$U = 4570, z = 4.743, p &lt; .000$</td>
</tr>
<tr>
<td>Median Practical subscale (SF) (IQR)</td>
<td>13.00 (7)</td>
<td>19.00 (9)</td>
<td>$U = 4515, z = 4.558, p &lt; .000$</td>
</tr>
</tbody>
</table>
Mediation.

A PROCESS mediational analysis (Model 4) was used to explore whether perceived stress was a mediator of the relationship between mastery and physical health (see Figure 1 for mediational model and path estimates). The overall relationship between mastery and physical health was significant $\beta = -0.97$, $SE = 0.35$, $t(109) = 2.76$, $p < .01$. Mastery was a significant predictor of perceived stress $\beta = -0.36$, $SE = 0.07$, $t(109) = 5.50$, $p < .001$ and perceived stress significantly predicted physical health $\beta = 1.19$, $SE = 0.50$, $t(109) = 2.36$, $p < .05$. A significant indirect effect of mastery on physical health through perceived stress was observed, $ME = -0.43$, $SE = 0.20$, 95% CI [-0.90, -0.86], mastery no longer predicted physical health (to $\beta = -0.53$, $SE = -0.39$, $t(109) = 1.38$, $p = .17$). Therefore, these results suggest that for parents of children with DD, the association between mastery and physical health is partly explained by perceptions of stress.

Moderation.

A moderation was conducted (Model 1 of the PROCESS model) to explore whether perceived support moderated the association between perceived stress and physical health. Analysis indicated that total perceived support moderated the pathway between perceived stress and physical health $\beta = 0.1259$, $SE = 0.056$, $t(109) = 2.25$, $p < .05$, neither of the subscales, emotional or practical, moderated this pathway. There is a significant indirect effect of perceived stress on physical health for medium $ME = 1.69$, $SE = 0.46$, 95% CI [.78, 2.61] and high $ME = 2.94$, $SE = 0.75$, 95% CI [1.44, 4.44] levels of perceived support but not for low levels of perceived support $ME = 0.45$, $SE = 0.65$, 95% CI [-0.83, 1.74] (see Figure 2 for illustration). These results indicate the interactive paths between factors which influence
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Table 2. Correlations among predictor variables and physical health in parents caring for children with developmental disabilities

<table>
<thead>
<tr>
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<th>1.</th>
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<th>3.</th>
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<th>7.</th>
<th>8.</th>
<th>9.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PHQ Physical health questionnaire</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Perceived stress scale (SF)</td>
<td>.312””</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>3. Mastery</td>
<td>-.258””</td>
<td>-.470””</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4. Total SDQ</td>
<td>-.001</td>
<td>.130</td>
<td>.075</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>5. SDQ Hyperactivity subscale</td>
<td>.007</td>
<td>.215”</td>
<td>.032</td>
<td>.804””</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6. SDQ Conduct subscale</td>
<td>-.012</td>
<td>.047</td>
<td>.094</td>
<td>.845””</td>
<td>.361””</td>
<td></td>
<td></td>
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<tr>
<td>7. Total perceived support</td>
<td>-.010</td>
<td>-.287””</td>
<td>.228”</td>
<td>-.040</td>
<td>-.105</td>
<td>.012</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Perceived emotional support</td>
<td>.009</td>
<td>-.274””</td>
<td>.254””</td>
<td>-.030</td>
<td>-.114</td>
<td>.025</td>
<td>.919””</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Perceived practical support</td>
<td>-.026</td>
<td>-.255””</td>
<td>.169</td>
<td>-.043</td>
<td>-.082</td>
<td>-.002</td>
<td>.926””</td>
<td>.702””</td>
<td></td>
</tr>
</tbody>
</table>

** **p < 0.01 level; * p < 0.05 level.
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physical health in parents, it can be seen that mastery, stress appraisal and social support are central components in protecting physical health but the effects are synergistic.

Figure 1. Mediation model for association between mastery, perceived stress and physical health, * $p < .05$, ** $p < .01$. 
Figure 2. Moderation of the association between perceived stress and physical health by perceived support in parents caring for children with DD.
The present study confirmed that caring for children with DD is more strongly associated with poor reported physical health than caring for a typically developing child (Gallagher & Whiteley, 2013; Lovell et al., 2011; Raina et al., 2005). The domains of physical health most affected were sleep, headaches, gastrointestinal and respiratory problems. These particular parents also reported higher perceived stress and lower scores on social support and self-mastery. Moreover, sleep problems (Gallagher et al., 2010; Hemmingsson, Stenhammar, & Paulsson, 2009) and headaches (Mörelius & Hemmingsson, 2013) have been highlighted as a significant cause of concern for these caring parents and tend to persist over time. In other caring contexts, sleep problems and headaches have also been found to be predictive of future health problems (McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2009) and have also been found to be associated with an increased risk of developing depression (Geerlings, Beekman, Deeg, & Van Tilburg, 2000). Further, relative to control parents, parents of children with DD self-rated health their health as lower than the control; it is worth noting that self-rated health is a predictor of future morbidity (Idler & Benyamini, 1999).

In terms of the psychosocial pathways driving this poor physical health in parents of children with DD, we found that perceived stress was associated with poor physical health. This aligns with other studies in the field (Gallagher & Whiteley, 2013; Lovell et al., 2011; Raina et al., 2005). Although child problem behaviours were not associated with poor physical health, the association was in the expected direction, i.e., it was positive; this lack of association may have been a consequence of only two subscales from the SDQ being used and not the full scale. A similar non-significant association was evident for social support, which is unlike other studies on psychological and physiological health outcomes in these...
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parents (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Gallagher & Whiteley, 2012; Lovell et al., 2012). However, our main aim was to explore the buffering role of social support on the perceived stress - physical health relationship. Social support has long been lauded as one of the principal psychosocial factors associated with health outcomes, both psychological and physical, and has previously been found to buffer stress in parents caring for children with DD (Dunn et al., 2001; Eisenhower, Baker, & Blacher, 2005). Even though our findings lend support to this line of research we have found that this interaction is more nuanced in this context. According to the stress buffering hypothesis, social support should only be associated with better physical health in high stress situations, but not in low stress situations (Cohen & Wills, 1985). Here, the association between perceived stress and physical health was only attenuated by high social support when stress was low and not high. This result may reflect that although some parents report high perceived support, the type of support they need when highly stressed may not be the support they perceive to have accessible to them. Studies on social support have categorised support into perceived and received dimensions; perceived, the individual’s appraisal of the support available to them when needed, has been found to predict better outcomes (Gallagher & Whiteley, 2012) whilst received support, reported receipt of support resources, has often been found to be associated with negative outcomes (Seidman, Shrout, & Bolger, 2006). Reasons proposed for the negative association between received support and outcomes are embarrassment at looking for support, the relationship between the giver of the support and the receiver or the support offered not matching the support needed (Uchino, 2009). Moreover, Reinhardt, Boerner, & Horowitz (2006) suggest that perceived support is beneficial to have but not to use; therefore it may be that perceived support may not be effective at high levels of stress as this is when actual support needs to be accessed.
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In fact, the stress buffering effect of social support has been shown to be most effective when the type of support matches the needs of the stressful event (Uchino, 2009). This finding may reflect that for these parents who are experiencing high levels of stress, perhaps they need formal or practical support such as respite or interventions. Indeed, the reported median for practical support here (13) was significantly lower than the median for emotional support (19) which could indicate that at higher levels of perceived stress emotional support is not sufficient. Further, recent qualitative studies have found that during periods of high stress when actual or practical social support is not available to parents, they rely on other less effective coping strategies (Gallagher, Phillips, Lee, & Carroll, Forthcoming; Gray, 2006). Similarly, parents experiencing high stress and who relinquish care of their child to social services are more likely to do so because they feel unsupported or do not have the right support to meet their needs (Nankervis, Rosewarne, & Vassos, 2011). Thus, in this context perceived availability of social support may not be enough to cope with the extraordinary demands of caring for children with DD, rather in high stress situations it is actual social support that is needed and support that matches the needs of the family (Nankervis et al., 2011).

Another psychological factor that was important in shielding against poor physical health in parents of children with DD is mastery. Self-mastery has been found to have important associations for health in other caring contexts (Roepke et al., 2008) and has implications for both physical and psychological functioning (Benyamini, Blumstein, Murad, & Lerner-Geva, 2011; Bovier, Chamot, & Perneger, 2004). The pathway to how mastery may be associated with physical health suggests that an interactive pathway between perceived stress, mastery and physical health, the results suggest that this is the case and an indirect path from mastery to perceived physical health through perceived stress was found. Therefore, the benefit of mastery to physical health appears to be through its effect on stress
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appraisal which is consistent with the transactional model of stress (Lazarus & Folkman, 1984). Support for the beneficial impact of stress appraisal on psychological outcomes in parents of children with DD is well substantiated (Trute et al., 2010). The results of this study also suggest that mastery may be a key factor in buffering physical health through its association with stress appraisal. Dealing with challenging behaviours from their children or struggling to access essential services may leave parents feeling they have little control over situations, which can often lead to feelings of loss of control, hopelessness or despondency (Van den Borne et al., 1999). A high sense of mastery can be seen to be a beneficial resource in dealing with stressful situations and through the interaction with stress appraisal has been shown to be beneficial for physical health. Moreover, given the importance of mastery and control for stress appraisals, it is welcome news that these concepts are now being employed in the development of psychosocial interventions for caregivers (Blom, Bosmans, Cuijpers, Zarit, & Pot, 2013; Solomon, Ono, Trimmer, & Goodlin-Jones, 2008). For example, psychosocial interventions that include methods for increasing mastery concentrate on building coping skills and in the first stage of the program parents were coached until they reached maximum mastery capacity after which they continued onto the second part of the program which involved parent directed interaction and these in turn impacted perceptions of stress and well-being. Similarly, parenting programmes for pre-schoolers with DD have been found to improve mastery and reduce stress in these parents (Ingersoll & Wainer, 2013), lending further support to our data.

Limitations

The limitations of the present study include the use of a cross sectional study ensuring inferences about causation are not possible. A further limitation is the self-selection of participants who responded to requests for participation, therefore our findings cannot be
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generalised. The reliance on self-report measures means that the study was also restricted to
the parents’ assessment of their own well-being; which can be affected by stress levels and
psychological health. Despite this, self-report measures are commonly used in caregiver
research and have been shown to be reliable and valid. Although a significant difference
was found in physical health between parental groups, the median score in physical health for
the parents of children with DD (53) was lower than reported in UK samples (Gallagher &
Whiteley, 2013). Additionally, perhaps the use of a scale such as the Family Support Scale
(Dunst et al., 1984) which focused formal and informal sources of support (helpfulness of
sources of support) support rather than on perceived support may have led to different results.
Finally, it is difficult to know what type of stressor was being perceived as most challenging
as the PSS does not capture such data. Future studies could try and assess this in more detail.

Conclusion

In summary, the present study extended research on the underlying pathways in which
stress is associated with physical health in parents of children with DD. In this study we have
demonstrated an interactive pathway between mastery, perceived stress, perceived support
and physical health. Our findings underscore the importance of providing actual support or
respite interventions during periods of high stress (Shattuck, Wagner, Narendorf, Sterzing, &
Hensley, 2011; Nankervis et al., 2011) to improve the health of these families. The results
also suggest that the mastery may be a key mechanism in shielding parents of children with
DD from poor physical health through its influence on stress appraisals. Finally, these data
indicate that social support and mastery may be key factors that influence how stress impacts
the physical health of parents of DD children and psychosocial interventions harnessing these
concepts are currently the focus of research efforts (Blom et al., 2013; Ingersoll & Wainer,
2013; Solomon, Ono, Timmer, & Goodlin-Jones, 2008). Moreover, identification of
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psychosocial resource factors may help health professional’s identify key targets for interventions that may, in turn, improve the health of parents of children with DD.
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Appendix

Appendix 1. Data summary of variables in study one

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (SD)</th>
<th>Range</th>
<th>Min/Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHQ</td>
<td>52.37 (12.801)</td>
<td>61</td>
<td>20-81</td>
</tr>
<tr>
<td>PSS</td>
<td>8.99 (2.623)</td>
<td>12</td>
<td>3-15</td>
</tr>
<tr>
<td>Mastery</td>
<td>17.39 (3.400)</td>
<td>15</td>
<td>9-24</td>
</tr>
<tr>
<td>SFS practical</td>
<td>13.89 (5.363)</td>
<td>22</td>
<td>6-28</td>
</tr>
<tr>
<td>SFS emotional</td>
<td>18.61 (5.113)</td>
<td>22</td>
<td>8-30</td>
</tr>
<tr>
<td>SFS Total</td>
<td>32.49 (9.665)</td>
<td>41</td>
<td>15-56</td>
</tr>
<tr>
<td>SDQ conduct</td>
<td>4.59 (2.781)</td>
<td>12</td>
<td>0-12</td>
</tr>
<tr>
<td>SDQ hyperactivity</td>
<td>7.48 (2.497)</td>
<td>13</td>
<td>1-14</td>
</tr>
<tr>
<td>SDQ total</td>
<td>12.08 (4.365)</td>
<td>23</td>
<td>1-24</td>
</tr>
</tbody>
</table>
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CHAPTER FOUR
Paper Two

Journal of Intellectual Disability Research
The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities
2015, V.59, pt. 10, pgs. 948-957
J Cantwell, O Muldoon, S. Gallagher
http://dx.doi.org/10.1111/jir.12205
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CHAPTER FIVE
Paper Three

Influence of Psychosocial Factors on the Health of Parents

CHAPTER SIX

Paper Four

CHAPTER SEVEN

General Discussion

The overarching aim of this thesis was to explore factors, beyond those already established in research (e.g., perceived stress, child behaviour and social support), that could contribute to an understanding of the variance in health outcomes for parents of children with disabilities. Although it is recognised that parental health outcomes are due to a confluence of risk and protective factors, the research presented in this thesis is in line with a more recent paradigm shift from identifying factors predictive of psychological distress (aetiology, lack of resources) to one of exploring factors (cognitive resources, personality factors, individual differences) that could buffer parents from the stress of caring and thus serve a protective function for parental health. Pottie, Cohen, and Ingram (2009) suggest that potential buffers of stress rather than predictors of distress need to be included in parental health research, however underlying psychosocial pathways to the maintenance of beneficial protective factors are poorly understood. In this thesis, for the first time in parental health research, role identities were explored as a potential underlying pathway to the maintenance of positive protective factors, i.e. mastery and self-esteem. We confirmed that parents caring for children with disabilities have poorer psychological and physical health compared to parents caring for typically developing children. To our knowledge no other study has tested for pathways in which factors, found to be associated with health in other stressful contexts, are implicated in parental health outcomes. Moreover, contingencies which underlie how these factors influence parental health were highlighted. Furthermore, we extended current knowledge by exploring how role factors account a substantial amount of variance in parental health outcomes.
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Thus, based on the literature review several gaps were identified and subsequently tested in this thesis. First, research aimed at exploring positive factors which buffer parental health have thus far failed to fully explain the mechanisms through which risk and protective factors interrelate to affect parental health (Glidden, Billings, & Jobe, 2006; Hamlyn-Wright & Ellis, 2007). Consequently, current models in parental health research do not successfully capture the synergistic relationships between these factors and are limited in exploring contingencies. Therefore, synergistic relationships between established risk and protective factors, mastery and self-esteem and the influence on parental health were explored. Second, as longitudinal studies are limited in parental health research, we explored psychological well-being across time and the factors which predicted variance in psychological well-being. Last, the association between role identities and health outcomes has been observed in other caring contexts (Savundranayagam & Montgomery, 2010) but had yet to be tested on parental health. This thesis was informed by principles of social psychology and also integrated strands of research from within stress and gerontology research (Savundranayagam & Montgomery, 2010; Thoits, 1983). Further, the juxtaposition between health and identity under stressful conditions has been established in other contexts (social identity; Haslam, O'Brien, Jetten, Vormedal, & Penna, 2005) however the function of identity had yet to be explored in parental health research. Here a role identity framework was identified as a promising tool to explore pathways to maintain positive affective states under conditions of stress as this sets out the potential protective function of role identities in the stress narrative. Thus, to increase understanding around parental adaptation we integrated key established factors in parental health research, i.e. perceived stress, child behaviour and social support with role identity research.
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**Brief Overview of Findings**

Successful evaluation of a role identity is proffered to exert a positive influence on levels of mastery and self-esteem a consequence of which should be improved psychological and physical well-being (Stets & Harrod, 2004; Wickrama, Conger, Lorenz, & Matthews, 1995). Although mastery and self-esteem are recognised as important resources in health research, little is known on how these resources interact with other pivotal factors to influence the health of parents of children with disabilities. Hence, we decided first to establish how these factors integrate with established risk and protective factors to influence parental health, we then examined psychological outcomes over time and finally how role identities influence health outcomes.

**Paper one.**

Parents of children with disabilities reported worse physical health, lower mastery and higher stress than control parents. Consistent with other studies (Raina *et al.*, 2005) poorer physical health was associated with perceived stress, lower mastery and less support. However the focus of this paper was on the pathways between these factors and we here we found that perceived stress mediated the pathway from mastery to physical health suggesting that mastery may influence stress appraisal to protect physical health. Although the pathway from perceived stress to physical health was moderated by support, this was only attenuated by high social support when stress was low and not high. Our findings for the role of social support were not as expected and run contra to the stress buffering hypothesis which suggests support is effective under conditions of high but not low stress (Cohen & Wills, 1985).
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**Paper two.**

In paper two we explored the synergistic relationship between stigma, self-esteem, social support and depressive symptomology. Stigma is recognised as extremely detrimental to parental well-being (Ali, Hassiotis, Strydom, & King, 2012) and here we found that parents of children with disabilities reported worse depressive symptomology, higher perceived stigma, lower self-esteem and less social support than control parents. We found that stigma was associated with poorer psychological well-being and this relationship was mediated by self-esteem. Additionally the benefit of emotional support for parents experiencing stigma-distress was only evident in those with low to medium self-esteem, high self-esteem alone was sufficient to protect psychological well-being from perceived stigma. Additionally we explored the role of carer identification; despite studies indicating that parents do not like to identify as a carer (Molyneaux, Butchard, Simpson, & Murray, 2011), we found that the majority of parents (80%) did so. We expected that identification might serve as a protective function (Savundranayagam & Montgomery, 2010) however here it was associated with higher stigma, more child behaviour problems and worse depressive symptomology.

**Paper three.**

The findings from the longitudinal study were reported in the third paper. The results suggested that psychological well-being in parents is constant across time; supporting previous research that has suggested poorer psychological health in parents is chronic (Glidden & Schoolcraft, 2003; Smith & Grzywacz, 2014). Perceived stress and mastery were associated with psychological well-being; however the greatest predictor of depression over time was baseline depression. We also explored the association between participation in roles and psychological well-being. Participating in employment was associated with higher
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mastery while participating in unpaid work was associated with higher self-esteem, however only participation in employment predicted less depressive symptomology at follow up.

**Paper four.**

In the final paper we continued the thread of caregiver identification from paper two and roles from paper three and extended this line of analysis to explore the function of role identity processes. The role identity processes examined were role content (importance and performance), multiple identities and role balance. Also of interest was whether identifying as a carer was associated with carer consistent behaviours, such as attending parental support groups. We found that stress was positively associated with depressive symptomology while mastery, self-esteem, social support, role balance, and multiple roles were significantly negatively associated with depressive symptomology. Caregiver identity was not associated with any caregiver behaviour however participating in support groups was associated with more emotional and practical support whilst accessing online support and participating in advocacy was associated with worse depressive symptomology. There was little variance in the role identities reported by parents however multiple roles were associated with less depressive symptomology but was also significantly negatively associated with child behaviour. Perceived performance in the role identity was differentially associated with protective factors and depressive symptomology. Perception of performance in the parent role predicted more depressive symptomology while perceived performance in role identities outside the parent role was associated with higher self-esteem and mastery, more support, role balance and less depressive symptomology. Role balance accounted for the most variance in depressive symptomology after which perceived performance in role identities outside parenting and spouse predicted less depressive symptomology.
Integration of Findings

Taken together the findings presented in these four papers support the higher levels of perceived stress and poorer physical and psychological health outcomes for parents of children with disabilities compared to parents of typically developing children. The aim of the thesis was to explore the function of role identities for parental health, particularly due to the psychological underpinnings i.e. mastery and self-esteem. We found that higher levels of mastery and self-esteem were extremely beneficial for parental health outcomes however our findings suggest that the relationships between these resources and existing risk and protective factors are nuanced and conditional. Despite plentiful research evidence suggesting that social support is a key protective factor against the stress of caring (Gallagher & Whiteley, 2012; Lovell, Moss, & Wetherall, 2012), support for the Stress Buffering Hypothesis has been inconsistent (Burton, Stice, & Seeley, 2004). Likewise, our results did not support the Stress Buffering Hypothesis - we found that for parents experiencing high stress support was not sufficient to protect physical health and only beneficial when parents reported low to medium perceived stress. However, parents reported higher levels of emotional rather than practical support suggesting that under high stress conditions practical support, such as respite, rather than emotional support may be required. The protective role of social support was also found to be conditional in the relationship between stigma, self-esteem and depressive symptomology. The benefit of support in protecting against stigma was evident in those with low to medium self-esteem, whereas high self-esteem alone appears to be sufficient to protect against depressive symptoms, independently of emotional support. These results suggest the protective role of support is contingent on the risk factor present and also which parental characteristic is most likely to buffer the risk. Although, it has been suggested that neither a sense-of-self or social support can mediate the impact of level of disability on parental health outcomes (Raina et al., 2005) we did find that mastery
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(associated with a sense-of-self in another caring context; Skaff, Pearlin, & Mullan, 1996), and social support synergistically can protect parental health under certain circumstances, i.e., low and medium stress.

However, given the evidence found here for the permanency of poorer psychological well-being across time, identifying pathways to the maintenance of these protective resources, i.e. mastery and self-esteem, is advantageous. We found that almost half the parents (40%) fit the criteria for possible clinical depression at both time points, supporting previous research that found that poorer psychological well-being of parents is chronic (Murphy, Christian, Caplin, & Young, 2007). This may be due to parents not looking after their own health (Gallagher & Hannigan, 2014) and without outside influence, such as screening, this may go untreated. Being employed was the only factor other than baseline anxiety to contribute to any variance in psychological well-being at follow up. Being employed was associated with mastery however despite being associated with psychological well-being at both time points, mastery did not predict any variance. Self-esteem was associated with participating in unpaid work. These results support role identity research which posits that successful enactment of a role will promote effective coping and adaptation (Wickrama et al., 1995) through an influence on these resources. Participating in employment may facilitate a sense-of-self, something that has found to be associated with mastery and better psychological well-being in other caring contexts (Skaff et al., 1996).

Freedman, Litchfield and Warfield (1995; p. 511) suggest that for parents employment may offer a “psychological source of fulfilment, respite and control over their lives”. Beresford, Rabiee, and Sloper (2007) found that parents reported losing aspects of their personal identity and these roles may be beneficial for psychological well-being by allowing parents to hold onto some personal identity outside of caring.
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Consistent with research in the area of multiple role identities (Thoits, 1983), the results suggest that multiple identities were associated with less depressive symptomology. Although parents reported a limited number of identities, additional roles may be beneficial by facilitating a sense-of-self, providing a method for positive evaluation or providing support. However, multiple roles were significantly negatively associated with child behaviour problems consequently parents with less roles may appraise child behaviour more negatively or indeed child behaviour problems may impede parents ability to participate in more roles. However role balance contributed the greatest variance in depressive symptomology, suggesting that for these parents, whose most central role identity (i.e. parenting) may be stressful, maintaining a balance between important role identities is essential. These results would suggest that there is a limit to the number of identities that are beneficial for parental being and in this context avoiding role conflict may be more beneficial for health outcomes (Marks & MacDermid, 1996). Supporting the suggestion by Eisenhower and Blacher (2006) that well-being risk for parents is associated with a shortage of roles rather than with role enhancement, here (although speculative) this may indicate that the benefits of multiple roles are in balancing a limited number of roles. However the results suggest that it is performance of the role identity that is important for psychological well-being. The ability to positively self-evaluate is extremely important for self-esteem and psychological well-being (Mann, Hosman, Schaalma, & de Vries, 2004) and holding a role identity where this can occur has been shown here to benefit psychological well-being. Eisenhower, Baker, and Blacher (2009) suggest that researchers should explore social roles beyond parenting as buffers for distress and here we found that role identities outside of parenting were predictive of less depressive symptomology; however it appears that what you think of what you do in these roles drives better psychological well-being.
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Practical and Theoretical Implications

Research conducted on the health of parents of children with disabilities should have the potential for practical utility. Given that the results shown in thesis indicate that parents of children with disabilities report worse physical and psychological health than parents with typically developing children, is it clear that parental health should be the starting point when designing parent training and interventions for children with disabilities. Current practise for families of children with disabilities adapts a family-centered and needs based approach. Parents are recognised as being central to the well-being of the child and are included as care partners in decisions regarding child care; however available resources are dependent on funding and when the funding is not available accessing resources is often highly fraught (Department Of Health, 2012). In these instances parents apply all their own resources into accessing services for their child often ignoring their own needs. The initiative by the Health Service Executive which is included in The National Carers Strategy: Recognised, Supported, Empowered, (2nd progress report) to encourage carers to attend an annual health check would have the potential to catch parents who have poorer psychological and physical health associated with caring. This underscores the importance of implementing this action as Gallagher and Hannigan (2014) found that parents of children with disabilities were not seeking treatment for depression.

Parents are encouraged to participate in parenting programs which aim to increase their coping skills around the child’s disability. The World Health Organisation in collaboration with Autism speaks have developed a new parent skills package for capacity building for caregivers of children with developmental delays and disorders (WHO, 2014). Parent training programs can through building parental coping and mastery skills lead to improved child behaviour and also have a positive influence on parental stress. As found in this thesis, high levels of mastery are an extremely valuable resource for parents of children
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with disabilities and are associated with many positive health outcomes. This program has been designed to be delivered by non-specialists in community settings and is currently being pilot tested in a number of regions; the program is available through the WHO. However, parental health needs to be a vital part of the child’s care package, a parent who is depressed or who has poor physical health may not see the benefit or may not be able to attend parental programs. Sustainability of care depends on parents’ psychological and physical health and as such should be an important part of the support system in place for the child. As we found here, poorer psychological well-being is likely to stay constant over time and without early identification and treatment can pose a significant risk. Untreated depression will have consequences, not only for parental functioning but may extend beyond the parent to influence the care of the child with a disability. Bromley, Hare, Davison, & Emerson (2004) point out that the health outcomes of parents do not fall under the responsibility of services for children, leaving parents to access services for themselves. However these parents put the needs of their children first and often do not look for help until they have reached burn-out. The finding that mastery and self-esteem both play a significant part in protecting parental health outcomes provides support for research and interventions which have placed an emphasis on the benefit of promoting mastery for decreasing stress for parents (Ingersoll & Wainer, 2013; Paczkowski & Baker, 2007; Raina et al. 2005; Solomon, Ono, Trimmer, & Goodlin-Jones, 2008).

These results support the need for practitioners to be aware of parents who are more susceptible to stigma, such as parents who perceive their child behaviour problems as beyond their control, and provide methods for dealing with perceived stigma. Given the association between stigma and social support, parents who perceive worse child behaviour may be at risk of becoming more isolated which is in turn detrimental for their psychological well-being. Additionally, as we found that attending support groups was associated with more
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support and less depressive symptomology, the benefits of attending these groups should be highlighted. Although parents may lose a sense-of-self due to the competing demands of caring on their time and energy, many parents also feel guilt when taking time away from caring for their child (Gallagher, Phillips, Oliver, & Carroll, 2008). Emphasising the positive association between psychological well-being and maintaining a sense-of-self through participation in roles, may help ease the burden or guilt parents feel when taking time for them.

Current policy

The findings of this thesis are in line with the vision of the current policy in Ireland towards carers as outlined in The National Carers Strategy: Recognised, Supported, Empowered, which was launched in 2012. This strategy seeks to recognise the role of the carer as a respected care partner, to support carers to maintain their own health and well-being and to empower carers to participate as fully as possible in economic and social life (Department of Health, 2012). This policy comprises four National goals containing 42 actions, including financial, educational and health components, which are to be met by cross departmental initiatives. Three progress reports in relation to the strategy have been produced to date, the last based on progress from September 2014 – September 2015. An assessment of progress based on the second progress report (Sept. 2013 – Sept. 2014) has been produced by The Carers Association (The Carers Association, 2015). They report that, thus far, the level of progress is slow with only one objective achieved in full; with a significant number of the initiatives not moving forward or indeed regressing. Although all initiatives proposed in the strategy would clearly have a positive impact of parental well-being these actions are not in line to be initiated during the life of the strategy.
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Of relevance to this thesis is the acknowledgement that the response for the older persons section has been strong but it is not clear how the needs of other cohorts of carers are being met, i.e. carers of young children with special needs. Initiatives included under National Goal 2 (i.e. to support carers to manage their physical, mental and emotional health and well – being) in the 2nd progress report, such as Action 2.1.2 – encourage carers to attend their GP for an annual health check, has the potential to treat parents who are suffering with poorer and chronic psychological well-being, as found in study three, however there has been no progress on this initiative. This action (2.2.1) changed in the third progress report to encourage carers to visit the G.P when appropriate however as indicated by the poorer health found in this thesis it is clear that parents are not looking after their own health and more clearer initiatives are needed to parents to look after their own health.

The aim of national goal 4 is to “empower carers to participate as fully as possible in economic and social life”. This goal perfectly ties into the findings of study four, that roles outside of the caring role were beneficial for psychological well-being. However, many of the actions included here, such as Action 4.2.3. Encourage work-life balance provisions that are needed to ensure that working arrangements are carer friendly, have been found to be regressive or to have shown no progress.

The “Programme for a Partnership Government” published on the 3rd May, 2016 has committed to a range of measures which when implemented should positively impact the lives of family carers (Family Carers Ireland, 2016; Irish Government, 2016). In light of our findings on the association between stigma and parental psychological health especially welcome is the recognition of the stigma associated with mental health and the commitment to create awareness through the education system (primary and secondary level). Creating awareness at a young age of difference and inclusion is in line with Article 8 (2b) of the Convention on the Rights of Persons with Disabilities and Optional Protocol (UNCRPD)
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which states that this a positive method of fostering an attitude of respect for the rights of persons with disabilities. An attitude of inclusion would decrease the perception of stigma by parents.

In recognition of the shift in research attention to exploring positive rather than risk factors in studies on parental health, Ruiz Robledillo & Moya-Albiol (2014) have suggested an integrative model based on current available evidence. They suggest this model could be useful when implementing preventive and intervention programmes for parents caring for children with disabilities. The data found in this thesis supports role identity processes as a useful addition to such a model. However in this proposed model, perceived control is conceived as a risk factor; we would propose that mastery (perceived control) should be treated as a protective factor and interventions that help parents build mastery are necessary. Existing models of parental adaptation such as the ABCX do include roles in the resource component (B) of the model however identifying the importance of the role identity and the implications for well-being of holding particular roles could potentially add another level of analysis to this model.

In this thesis we provided a better understanding of the synergistic pathways between established risk and protective factors and the personal resources of the parent. In doing so we highlighted mastery and self-esteem as key mechanisms in shielding parental psychological and physical health from key risk indicators, i.e. stress and stigma. We extended the social support literature by showing that for parents of children with disabilities, the type of support required is conditional, i.e. either on the level of perceived stress or the level of resources such as self-esteem. Our findings also underscore the importance of providing actual support or respite interventions during periods of high stress. The exploration of role identities in parental research is novel and highlights the importance of role identities outside of the caring role for parental health outcomes. We showed that
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parents perception of performance in a role identity is significant for health outcomes and suggest that the opportunity to positively self-evaluate in a role identity is extremely beneficial when someone has a main role identity that is stressful i.e. caring.

Limitations

Recruitment.

The present thesis has a number of limitations both in recruitment and the methodology. One of the most significant limitations in parental research is recruitment. These parents are extremely busy and do not have the time and energy to participate in research. As with much of the research in health, the self-selection of participants could constitute a bias; parents who chose to participate may have better health, more time or support allowing them to participate. However, the results found here are in line with parent health studies using data from large scale population studies (Gallagher & Hannigan, 2014). Moreover, it was difficult to retain parents for the longitudinal study; despite 76 (62.8%) parents indicating they would participate in further studies only 45 (37.2%) did so when contacted. The low level of interest in participating in a follow up study may have been due to the length of the initial survey and there may have been apprehension that a further study would be similar. Due to the difficulty in recruitment, data from the same participants were reported in all four papers. However, due to the similarity between the group of parents who participated in this study and the data from parents across empirical papers it was considered that these parents were sufficiently representative of parents of children with disabilities as a population to use data from the same participants to explore the hypothesis set out in this thesis.
Methodological.

Unexpectedly, we did not find child behaviour was associated with the outcome factors (psychological or physical) in our analysis. This is contra to most research on parental health where child behaviour is the most significant factor in driving stress and poorer parental health (Gallagher & Whiteley, 2013; Lovell, Moss, & Wetherall, 2015). This may have been due to using only two subscales, conduct and hyperactivity, and not the whole scale. In the longitudinal study only measures of outcome (i.e. HADS and PHQ) were collected at follow up. As the study was conducted over a short period of time, we opted not to include risk and protective factors at follow up as these factors are not likely to change substantially over the short term. However, employment status may have changed over time which could have influenced the findings.

The role identity framework on which this thesis was premised was difficult to operationalise in this context. Role identity as suggested by Burke and Stets (2009; p18) is an amalgam of ideas and preceding theories such as symbolic interactionism (Stryker, 1980), identity theory (Burke, 1991), perceptual control theory (Burke, 2004) and self-verification theory (Swann, 2011), and as such what exactly role identity is and how it is measured is unfinished and continually expanding. As a result, research centred on role identity tenets is considered to be based on a framework rather than a theory. Thus far, role identity concepts are quite theoretical and research applying a role identity framework has included a limited type of role identities, which may be due to the measures available. Much of the research is on role identities where a counter identity is available and as such identity discrepancy or identity verification is easier to measure (e.g., spouse; Burke & Stets, 1999 and gender role identities, Burke & Cast, 1997; Stets & Biga, 2003). Additionally, many of the measures are
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quite complex (e.g., the use of semantic differential scales) and as such are only applicable in
certain contexts.

Caregiver identity theory (Montgomery & Kosloski, 2013) based on a role identity
framework, identified that for spouses of Alzheimer sufferers discrepancy between the spouse
and carer role led to distress. However, in this context there were dual but separate identities
present and as such when the spouse was able to align their caring behaviours with a carer
identity they consequently experienced less distress. However, for parents of children with
disabilities their identities are more complex and the parent and carer identities less distinct.
And so, to avoid alienating participants and risk the non-completion of the survey, the
identity measures we used in this thesis were less complex. Our main identity interests were
(a) whether parents who identified as a carer would adapt carer consistent behaviours and
would these behaviours buffer health outcomes from stress; (b) would participation in
important roles outside the parenting/caring role attenuate the stress of caring; (c) would
multiple role identities be protective in this context. Of further interest was exploring the
underlying pathway from role identities to health outcomes via mastery and self-esteem. For
that reason a role identity framework was considered an ideal fit to answer these questions.

Additional analyses

Additional analyses were conducted on study four data to test whether the HADS
anxiety subscale was associated with the psychosocial variables included therein. The
patterns of associations for the anxiety subscale were similar to those of the depression
subscale (see Table 1) albeit there were fewer associations between anxiety and all other
factors. Additionally, the association between the HADS subscales, anxiety and depression,
and stigma were analysed. The finding were similar to those of study two; stigma was
significantly associated with depression, $r = .223, p = .014$ however there was no association with the anxiety subscale, $r = .152, p = .096$.

**Future Research**

The majority of parents in this study were married, however the preponderance of dual parent families caring for a child with disabilities has fallen over the years from 80.5% in 1996 to 74.3% in 2006 with a related rise in lone parent carers (Kelly, Craig, McConkey, & Mannan, 2009). This increase in lone parenting is most evident in parents caring for children with mild to moderate intellectual disabilities under the age of 20; which has doubled within a decade. Whether this phenomenon is indicative of the purportedly higher divorce rates in parents of children with disabilities or support for the rise in children diagnosed with ASD over the last decade (Baird *et al.*, 2006; CDC, 2014b) is not evident. However, as support from a partner is associated with less stress when caring for a child with disabilities (Gerstein, Crnic, Blacher, & Baker, 2009) these parents are especially vulnerable and may be at greater risk for poverty and lack of social support (Bromley *et al.*, 2004; Olsson & Hwang, 2001). The data reported here supports participation in roles outside of caring as being associated with less depressive symptomology. However, the majority of parents participating in these roles were married and support from their partner may have facilitated participation in roles. Brown *et al.* (2008) advise that more care should be made in screening for single parents especially for psychosocial stressors and mental health issues. Given the reported trends and the evidence found in thesis for both poorer psychological and physical health for caring parents, this is a vital line of future research.

Another extremely fruitful line of research would be in determining why parents do not access health support for themselves. Parental health is vital for sustainability of care therefore promoting the importance of their own health maintenance as being as important as
Influence of Psychosocial Factors on the health of parents

the care of the child is vital. Delineation of the reasons for parents not accessing care for themselves would be an extremely valuable line of research. Identifying whether this was due to lack of time, financial constraints, stigma or a fear that they would be perceived as not coping would be extremely useful for implementing interventions or indeed informing policy. Given the increase in developmental disabilities such as autism (CDC, 2014b), this line of research is not only timely but also necessary in alleviating a major public health concern.

Conclusion

In summary, in the present thesis we extended knowledge on parental health by applying a role identity framework to enhance the understanding of the variance in health outcomes for parents of children with disabilities. We demonstrated how resources underpinning role identities, i.e. mastery and self-esteem, work synergistically with more established factors (stress, stigma and support) to influence parental psychological and physical health outcomes. In doing so we responded to recent calls to extend research on factors associated with physical health in parents of children with disabilities (Miodrog & Hodapp, 2010), to examine the influence of perceived stigma on parental well-being (Ali et al. 2012) and to explore the benefit of social roles beyond parenting for parental health (Eisenhower et al., 2009). Further, an analysis of role identities is novel in parental health research and here we demonstrated how multiple role identities, role balance and rolecontent were associated with better psychological well-being for parents of children with disabilities.
Influence of Psychosocial Factors on the health of parents

Table 1. Study Four - Associations between Psychosocial Variables and Psychological Well-Being (N=121)

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
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<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.HADS anxiety</td>
<td></td>
<td></td>
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<tr>
<td>2.HADS depression</td>
<td>.529**</td>
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<tr>
<td>3.HADS total</td>
<td>.881**</td>
<td>.867**</td>
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<tr>
<td>4.PSS</td>
<td>.560**</td>
<td>.444**</td>
<td>.572**</td>
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<tr>
<td>5.SDQ conduct</td>
<td>.005</td>
<td>-.180</td>
<td>-.096</td>
<td>-.007</td>
<td></td>
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<tr>
<td>6.SDQ hyperactivity</td>
<td>-.175</td>
<td>-.085</td>
<td>-.150</td>
<td>-.206*</td>
<td>.238**</td>
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<tr>
<td>7.SDQ total</td>
<td>-.091</td>
<td>-.161</td>
<td>-.144</td>
<td>-.107</td>
<td>.790**</td>
<td>.783**</td>
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<tr>
<td>8.Self-esteem</td>
<td>.447**</td>
<td>.344**</td>
<td>.453**</td>
<td>.305**</td>
<td>-.097</td>
<td>-.163</td>
<td>-.166</td>
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<tr>
<td>9.Mastery</td>
<td>.475**</td>
<td>.493**</td>
<td>.553**</td>
<td>.405**</td>
<td>-.057</td>
<td>-.031</td>
<td>-.054</td>
<td>.449**</td>
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<tr>
<td>10.Support (total)</td>
<td>.184*</td>
<td>.284**</td>
<td>.267**</td>
<td>.282**</td>
<td>-.089</td>
<td>-.170</td>
<td>-.150</td>
<td>.145</td>
<td>.249**</td>
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</tr>
<tr>
<td>11.How many roles</td>
<td>.103</td>
<td>.202*</td>
<td>.164</td>
<td>.074</td>
<td>-.162</td>
<td>-.225*</td>
<td>-.221*</td>
<td>.103</td>
<td>.142</td>
<td>.172</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>12.Role balance</td>
<td>.284**</td>
<td>.612**</td>
<td>.503**</td>
<td>.406**</td>
<td>-.070</td>
<td>-.028</td>
<td>-.055</td>
<td>.392**</td>
<td>.610**</td>
<td>.296**</td>
<td>.203*</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>13.Role 1 performance</td>
<td>-.038</td>
<td>-.039</td>
<td>-.029</td>
<td>.114</td>
<td>-.141</td>
<td>-.092</td>
<td>-.028</td>
<td>.403**</td>
<td>.183</td>
<td>.140</td>
<td>.066</td>
<td>.151</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>14.Role 2 performance</td>
<td>.007</td>
<td>.195*</td>
<td>.088</td>
<td>-.010</td>
<td>-.105</td>
<td>-.075</td>
<td>-.063</td>
<td>.252**</td>
<td>.281**</td>
<td>.189*</td>
<td>-.016</td>
<td>.322**</td>
<td>.131</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.Role 3 performance</td>
<td>.178</td>
<td>.313**</td>
<td>.241**</td>
<td>.159</td>
<td>-.129</td>
<td>-.128</td>
<td>.021</td>
<td>.170</td>
<td>.308**</td>
<td>.141</td>
<td>.173</td>
<td>.324**</td>
<td>-.035</td>
<td>.152</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**. Sig. at the 0.01 level (2-tailed), *. Sig. at the 0.05 level (2-tailed).
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References


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### APPENDIX A

**QUESTIONNAIRES**

**STUDY ONE**

### Section 1: About yourself

<table>
<thead>
<tr>
<th>Age (Parent/Guardian):</th>
<th>Gender:</th>
<th>Marital Status:</th>
<th>Ethnicity:</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your highest level of education:</td>
<td>Are you employed (paid work) outside the home:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**How would you best describe your occupation? (please circle)**

- [ ] 1 Professional e.g. Doctor/
- [ ] 2 Managerial e.g. P.A.
- [ ] 3 Skilled non-manual e.g. nurse
- [ ] 4 Skilled manual e.g. Craftsman
- [ ] 5 Partly Skilled e.g. Bus Driver
- [ ] 6 Unskilled e.g. Labourer
- [ ] Lawyer

If yes, how many hours do you spend at employable (paid) work per week: (please circle)

- [ ] 0
- [ ] 1 - 15
- [ ] 16 - 24
- [ ] 25 - 34
- [ ] 35 - 39
- [ ] 40
- [ ] 40+

Do you do any unpaid work outside the home (e.g., voluntary work)? Yes / No
Where type of unpaid work do you do?
Are you currently a student, doing any courses (full/part time)? Yes / No
What courses are you doing?

What is your household income? (please circle)

- [ ] 0 - €20,000
- [ ] €20,001 - €40,000
- [ ] €40,001 - €60,000
- [ ] €60,001 - €80,000
- [ ] Over €80,001

Do you receive carer’s allowance? (Please circle) Yes / No

### Section 2: About your child (ren)

<table>
<thead>
<tr>
<th>How many children do you have?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>Child 1</td>
</tr>
<tr>
<td>Child 2</td>
</tr>
<tr>
<td>Child 3</td>
</tr>
<tr>
<td>Child 4</td>
</tr>
<tr>
<td>Child 5</td>
</tr>
</tbody>
</table>
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Are you the main caregiver for the child (ren) with special needs?

Does your child (ren) with special needs live with you permanently?

For the child(ren) with special needs, how many hours, a day on average, do you spend caring for them?

Do you consider yourself a carer?       Yes / No

What physical needs does your child(ren) have?

Section 3: This section asks you about your child (ren). Please give your answers on the basis of the child’s behaviour over the last SIX MONTHS. Circle only one number for each question.

1 = Not true       2 = Somewhat true       3 = Certainly true

1. Restless, overactive, cannot stay still for long
2. Often has temper tantrums or hot tempers
3. Generally obedient - usually does what adults request
4. Constantly fidgeting or squirming
5. Often fights with other children or bullies them
6. Easily distracted, concentration wanders
7. Often argumentative with adults
8. Can stop and think things out before acting
9. Can be spiteful to others
10. Sees tasks through to the end, good attention span

This section asks you about the facilitators who provide assistance for your child(ren) with special needs, for you and for the family e.g., Please list the service providers.
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Section 4: This section is about your feelings and thoughts during the LAST MONTH. In each case, indicate by ticking in the appropriate space how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question.

<table>
<thead>
<tr>
<th>1 = Never</th>
<th>2 = Almost Never</th>
<th>3 = Sometimes</th>
<th>4 = Fairly often</th>
<th>5 = Very often</th>
</tr>
</thead>
</table>

In the past month how often have you...

1. felt that you were unable to control the important things in your life?

2. felt confident about your ability to handle personal problems?

3. felt that things were going your way?

4. felt difficulties were piling up so high that you could not overcome them

Section 5: This section asks you about people’s attitudes

What do you think when you hear the term carer? (Please write in)

How much would you say you agree with the following statements? (Please circle the one you agree with)

<table>
<thead>
<tr>
<th>1 = Strongly disagree</th>
<th>2 = Disagree</th>
<th>3 = Agree</th>
<th>4 = Strongly agree</th>
</tr>
</thead>
</table>

1. “I feel that people think less of a person who provides care for someone else”

2. “I feel I am treated differently when I am with my child(ren) with special needs “

3. “I feel there is a stigma that goes with caring “

Section 6: This section is about the roles in your life.

What are the roles you carry out? Here are some examples, you can be a student, a mother etc. (Please write in as many as you want).
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Please choose four roles from your list above. In each section below please pick one of these roles, state what the role is and then circle the most appropriate answer, for example if one of your roles is a nurse, in the role 1 section state...nurse, and so on for each role

<table>
<thead>
<tr>
<th>Role 1 (please indicate the role)</th>
<th>1. How important is being this role to how you think about yourself?</th>
<th>Not at all important</th>
<th>Somewhat important</th>
<th>Important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. How important is being this role to how you want others to think about you?</td>
<td>Not at all important</td>
<td>Somewhat important</td>
<td>Important</td>
<td>Very important</td>
</tr>
<tr>
<td></td>
<td>3. How well do you feel you perform in this role?</td>
<td>Not at all well</td>
<td>Fair</td>
<td>Well</td>
<td>Very well</td>
</tr>
<tr>
<td></td>
<td>4. How well do you think others would think you perform in this role?</td>
<td>Not at all well</td>
<td>Fair</td>
<td>Well</td>
<td>Very well</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Role 2 (please indicate the role)</th>
<th>1. How important is being this role to how you think about yourself?</th>
<th>Not at all important</th>
<th>Somewhat important</th>
<th>Important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. How important is being this role to how others generally think about you?</td>
<td>Not at all important</td>
<td>Somewhat important</td>
<td>Important</td>
<td>Very important</td>
</tr>
<tr>
<td></td>
<td>3. How well do you feel you perform this role?</td>
<td>Not at all well</td>
<td>Fair</td>
<td>Well</td>
<td>Very well</td>
</tr>
<tr>
<td></td>
<td>4. How well do you think others would think you perform this role?</td>
<td>Not at all well</td>
<td>Fair</td>
<td>Well</td>
<td>Very well</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Role 3 (please indicate the role)</th>
<th>1. How important is this role to how you think about yourself?</th>
<th>Not at all important</th>
<th>Somewhat important</th>
<th>Important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. How important is being this role to how others generally think about you?</td>
<td>Not at all important</td>
<td>Somewhat important</td>
<td>Important</td>
<td>Very important</td>
</tr>
<tr>
<td></td>
<td>3. How well do you feel you perform this role?</td>
<td>Not at all well</td>
<td>Fair</td>
<td>Well</td>
<td>Very well</td>
</tr>
<tr>
<td></td>
<td>4. How well do you think others would think you perform this role?</td>
<td>Not at all well</td>
<td>Fair</td>
<td>Well</td>
<td>Very well</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Role 4 (please indicate the role)</th>
<th>1. How important is this role to how you think about yourself?</th>
<th>Not at all important</th>
<th>Somewhat important</th>
<th>Important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. How important is being this role to how others</td>
<td>Not at all</td>
<td>Somewhat</td>
<td>Important</td>
<td>Very important</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th>generally think about you?</th>
<th>Important</th>
<th>Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. How well do you feel you perform <em>this role</em>?</td>
<td>Not at all well</td>
<td>Fair</td>
</tr>
<tr>
<td>4. How well do you think others would think you perform <em>this role</em>?</td>
<td>Not at all well</td>
<td>Fair</td>
</tr>
</tbody>
</table>

Section 7: This section is about how you balance the important roles in your life

“At times do you find the important roles you picked in the previous section conflict with each other? (Please circle)

<table>
<thead>
<tr>
<th>Very Frequently</th>
<th>Frequently</th>
<th>Occasionally</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = Strongly agree</td>
<td>2 = Agree</td>
<td>3 = Neutral</td>
<td>4 = Disagree</td>
<td>5 = Strongly disagree</td>
</tr>
</tbody>
</table>

How much would you say you agree with the following statements? (Please circle the one you agree with)

1. “I am pretty good at keeping different parts of my life in balance: I generally don’t let things slide”
2. “Nowadays I seem to enjoy every part of my life equally well”
3. “Work, leisure, family time - I find satisfaction in everything I do”
4. “I try to put a lot of myself into everything I do”

Section 8: This section is about the amount of control you feel you have

<table>
<thead>
<tr>
<th>1 = Strongly disagree</th>
<th>2 = Disagree</th>
<th>3 = Agree</th>
<th>4 = Strongly agree</th>
</tr>
</thead>
</table>

How much would you say you agree with the following statements? (Please circle the one you agree with)

1. “I have little control over the things that happen to me?”
2. “There is really no way I can solve some of the problems that I have”
3. “There is little I can do to change many of the important things in my life”
4. “I often feel helpless in dealing with the problems of life”
5. “Sometimes I feel that I’m being “pushed around” in life”
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6. “What happens to me in the future mostly depends on me” 1 2 3 4

7. “I can do just about anything I really set my mind to do” 1 2 3 4

Section 9: The following items focus on how you feel about yourself.

<table>
<thead>
<tr>
<th>Item</th>
<th>1 = Strongly disagree</th>
<th>2 = Disagree</th>
<th>3 = Agree</th>
<th>4 = Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “I feel I am a person of worth at least on an equal basis with others”</td>
<td></td>
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</tr>
<tr>
<td>2. “I feel that I have a number of good qualities”</td>
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<tr>
<td>3. “All in all, I am inclined to feel that I am a failure”</td>
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<tr>
<td>4. “I am able to do things as well as most other people”</td>
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<tr>
<td>5. “I feel that I do not have much to be proud of”</td>
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<tr>
<td>6. “I take a positive attitude toward myself”</td>
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<tr>
<td>7. “On the whole, I am satisfied with myself”</td>
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<tr>
<td>8. “I wish I could have more respect for myself”</td>
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<tr>
<td>9. “I certainly feel useless at times”</td>
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<td></td>
<td></td>
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<tr>
<td>10. “At times, I think I am no good at all”</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

1 = Never 2 = Once in a while 3 = Sometimes 4 = Often 5 = Quite often
### Section 10: Listed below are different types of assistance which people sometimes feel helpful. Please answer all the questions. Please circle only one number in each section. How often is each of the following kinds of support available to you, if you need it?

<table>
<thead>
<tr>
<th></th>
<th>Type of Support</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Someone to talk about things that worry you</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Someone to help take care of your child</td>
<td></td>
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<tr>
<td>3.</td>
<td>Someone to talk to when you have questions about raising your child</td>
<td></td>
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<tr>
<td>4.</td>
<td>Someone who will help you financially if you need it</td>
<td></td>
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<tr>
<td>5.</td>
<td>Someone to encourage or keep you going when things seem hard</td>
<td></td>
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<tr>
<td>6.</td>
<td>Someone who accepts your child regardless of how (s)he act</td>
<td></td>
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<tr>
<td>7.</td>
<td>Someone to help with household chores</td>
<td></td>
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<tr>
<td>8.</td>
<td>Someone to relax or a joke with</td>
<td></td>
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<tr>
<td>9.</td>
<td>Someone to do things with your child</td>
<td></td>
<td></td>
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<tr>
<td>10.</td>
<td>Someone to provide you or your child with transportation</td>
<td></td>
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<tr>
<td>11.</td>
<td>Someone to deal with agencies or organisations when you feel you cannot</td>
<td></td>
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<tr>
<td>12.</td>
<td>Someone who tells you about services for your child or family</td>
<td></td>
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<tr>
<td>13.</td>
<td>How often do you attend support groups for parents /relatives of children with special needs?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>14.</td>
<td>How often do you make use of online support groups for parents/relatives of children with special needs? E.g., chat rooms, Facebook</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>15.</td>
<td>Do you take part in fund raising for any organisation that provides services for children with special needs or their families</td>
<td></td>
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<tr>
<td>16.</td>
<td>Do you take part in advocacy (e.g., protests or marches) to highlight issues involving caring for children with special needs or their families</td>
<td></td>
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</tbody>
</table>
This section is about how you feel in general. Read each item and circle the appropriate answer which comes closest to how you have been feeling in the PAST WEEK. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

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<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1. I feel tense or wound up</td>
<td></td>
<td></td>
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<tr>
<td>2. I still enjoy the things I used to enjoy</td>
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<tr>
<td>3. I get a sort of frightened feeling as if something awful is about to happen</td>
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<td>4. I can laugh and see the funny side of things</td>
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<td>5. Worrying thoughts go through my mind</td>
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<tr>
<td>6. I feel cheerful</td>
<td></td>
<td></td>
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<tr>
<td>7. I can sit at ease and feel relaxed</td>
<td></td>
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<tr>
<td>8. I feel as if I am slowed down</td>
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<tr>
<td>9. I get a sort of frightened feeling like butterflies in the stomach</td>
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<tr>
<td>10. I have lost interest in my appearance</td>
<td></td>
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<tr>
<td>11. I feel restless as if I have to be on the move</td>
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<tr>
<td>12. I look forward with enjoyment to things</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>13. I get sudden feelings of panic</td>
<td></td>
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<tr>
<td>14. I can enjoy a good book or radio or TV programme</td>
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</tbody>
</table>

<p>| | | | |</p>
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<tbody>
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</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Most of the time</th>
<th>A lot of the time</th>
<th>Time to time</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
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<tr>
<td>3.</td>
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<td></td>
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<td>4.</td>
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<td>5.</td>
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<td>6.</td>
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<td>7.</td>
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<td>8.</td>
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<tr>
<td>9.</td>
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<td>10.</td>
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<td>11.</td>
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<tr>
<td>12.</td>
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<td>13.</td>
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<tr>
<td>14.</td>
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</tbody>
</table>
### Section 12: Physical Health Questionnaire

The following items focus on how you have been feeling physically during the last year and how often it happened.

<table>
<thead>
<tr>
<th></th>
<th>Not at all (1)</th>
<th>Rarely (2)</th>
<th>Once in a while (3)</th>
<th>Some of the time (4)</th>
<th>Fairly often (5)</th>
<th>Often (6)</th>
<th>All of the time (7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. have you had difficulty getting to sleep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>2. have you woken up during the night?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3. have you had nightmares or disturbing dreams?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>4. has your sleep been peaceful and undisturbed?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>5. have you experienced headaches?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>6. did you get a headache when there was a lot of pressure to get things done?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>7. did you get a headache when you were frustrated because things were not going the way they should have or when you were annoyed at someone?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>8. have you suffered from an upset stomach (indigestion)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>9. did you have to watch what you ate carefully to avoid stomach upsets?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>10. did you feel nauseated (‘sick to the stomach’)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>11. were you constipated or did you suffer from diarrhoea?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>12. do you have minor colds? (that made you feel uncomfortable but don’t keep you sick in bed or off work)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>13. have you had respiratory infections more severe than minor colds that “laid you low” (bronchitis, sinusitis)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

1. Have you been to see your G.P. for any of these symptoms? **Yes / No**

2. What medication were you prescribed

3. If you suffer from any of the symptoms above, are they related to a diagnosis e.g., my symptoms are related
to my gluten intolerance rather than stress. If they are, please indicate what the diagnosis is:

4. Compared to others of your age and sex, how would you rate your general health? (Please circle one)

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Above average</th>
<th>Average</th>
<th>Below average</th>
<th>Very poor</th>
</tr>
</thead>
</table>

Thank you

Thank you so much for completing this questionnaire, your help is valuable in conducting this study. I realise I have asked you a lot of personal questions and appreciate your cooperation in this research.

Would you be willing to be contacted to take part in follow up research?
If yes, please provide an email address
______________________________
# Influence of Psychosocial Factors on the Health of Parents

## Section 1: About yourself, what is your .....

<table>
<thead>
<tr>
<th>Age (Parent/Guardian):</th>
<th>Gender:</th>
<th>Marital Status:</th>
<th>Ethnicity:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

What is your highest level of education: Are you employed (paid work) outside the home:

How would you best describe your occupation? (please circle)

1. Professional e.g., Doctor/ Lawyer
2. Managerial e.g., P.A.
3. Skilled non-manual e.g., nurse
4. Skilled manual e.g., Craftsman
5. Partly Skilled e.g., Bus Driver
6. Unskilled e.g., Lab

If anything other than the above, please indicate:

If yes, how many hours do you spend at employable (paid) work per week? (please circle)

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1 - 15</th>
<th>16 - 24</th>
<th>25 - 34</th>
<th>35 - 39</th>
<th>40</th>
<th>40+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Do you do any unpaid work outside the home (e.g., voluntary work)? Yes / No

What type of unpaid work do you do?

Are you currently a student, doing any courses (full/part time)? Yes / No

What courses are you doing?

What is your household income? (please circle)

<table>
<thead>
<tr>
<th></th>
<th>0 - €20,000</th>
<th>€20,001 - €40,000</th>
<th>€40,001 - €60,000</th>
<th>€60,001 - €80,000</th>
<th>Over €80,001</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

How many children under the age of 18 do you have and what are their ages?

## Section 2: This section is about your feelings and thoughts during the LAST MONTH. In each case, indicate by ticking in the appropriate space how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question.

<table>
<thead>
<tr>
<th></th>
<th>1 = Never</th>
<th>2 = Almost Never</th>
<th>3 = Sometimes</th>
<th>4 = Fairly often</th>
<th>5 = Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. felt that you were unable to control the important things in your life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Influence of Psychosocial Factors on the health of parents

<table>
<thead>
<tr>
<th>2. felt confident about your ability to handle personal problems?</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. felt that things were going your way?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. felt difficulties were piling up so high that you could not overcome them</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Section 3: This section asks you about people’s attitudes

What do you think when you hear the term carer? (Please write in)

How much would you say you agree with the following statements? (Please circle the one you agree with)

<table>
<thead>
<tr>
<th>2 = Strongly disagree</th>
<th>2 = Disagree</th>
<th>3 = Agree</th>
<th>5 = Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.“I feel that people think less of a person who provides care for someone else”</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2.”I feel that people are treated differently when with child(ren) with special needs “</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. “I feel there is a stigma that goes with caring “</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Section 4: This section is about the roles in your life.

What are the roles you carry out that are most important to you, for example you may be a student, a mother, a friend etc. List as many as you want.

Please choose four roles from your list above. In each section below please pick one of these roles, state what the role is and then circle the most appropriate answer, for example if one of your roles is a nurse, in the role 1 section state….nurse, and so on for each role

<table>
<thead>
<tr>
<th>Role 1 (please indicate the role)</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Quite</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How important is this role to how you think about yourself?</td>
<td>Not at all</td>
<td>Somewhat</td>
<td>Quite</td>
<td>Very</td>
</tr>
<tr>
<td>2. How important is this role to how you want others to think about you?</td>
<td>Not at all</td>
<td>Somewhat</td>
<td>Quite</td>
<td>Very</td>
</tr>
<tr>
<td>3. How well do you feel you perform in this role?</td>
<td>Not at all</td>
<td>Somewhat</td>
<td>Quite</td>
<td>Very</td>
</tr>
<tr>
<td>4. How well do you think others would think you perform in this role?</td>
<td>Not at all</td>
<td>Somewhat</td>
<td>Quite</td>
<td>Very</td>
</tr>
</tbody>
</table>
Influence of Psychosocial Factors on the health of parents

### Role 2

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Quite</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How important is this role to how you think about yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. How important is this role to how you want others to think about you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. How well do you feel you perform this role?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. How well do you think others would think you perform this role?</td>
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</tbody>
</table>

### Role 3

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Quite</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How important is this role to how you think about yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. How important is this role to how you want others to think about you?</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>3. How well do you feel you perform this role?</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. How well do you think others would think you perform this role?</td>
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</table>

### Role 4

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>Somewhat</th>
<th>Quite</th>
<th>Very</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How important is this role to how you think about yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. How important is this role to how you want others to think about you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. How well do you feel you perform this role?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. How well do you think others would think you perform this role?</td>
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</tbody>
</table>

### Section 5: This section is about how you balance the important roles in your life

“At times, do you find the important roles you picked in the previous section conflict with each other? (Please circle)

Very Frequently    Frequently    Occasionally    Rarely    Never
Influence of Psychosocial Factors on the health of parents

<table>
<thead>
<tr>
<th>How much would you say you agree with the following statements? (Please circle the one you agree with)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “I am pretty good at keeping different parts of my life in balance: I generally don’t let things slide”</td>
</tr>
<tr>
<td>2. “Nowadays I seem to enjoy every part of my life equally well”</td>
</tr>
<tr>
<td>3. “Work, leisure, family time - I find satisfaction in everything I do”</td>
</tr>
<tr>
<td>4. “I try to put a lot of myself into everything I do”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section 6: This section is about the amount of control you feel you have</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “I have little control over the things that happen to me?”</td>
</tr>
<tr>
<td>2. “There is really no way I can solve some of the problems that I have”</td>
</tr>
<tr>
<td>3. “There is little I can do to change many of the important things in my life”</td>
</tr>
<tr>
<td>4. “I often feel helpless in dealing with the problems of life”</td>
</tr>
<tr>
<td>5. “Sometimes I feel that I’m being “pushed around” in life”</td>
</tr>
<tr>
<td>6. “What happens to me in the future mostly depends on me”</td>
</tr>
<tr>
<td>7. “I can do just about anything I really set my mind to do”</td>
</tr>
</tbody>
</table>
Influence of Psychosocial Factors on the health of parents

**Section 7: The following items focus on how you feel about yourself.**

<table>
<thead>
<tr>
<th>1 = Strongly disagree</th>
<th>2 = Disagree</th>
<th>3 = Agree</th>
<th>4 = Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. “I feel I am a person of worth at least on an equal basis with others”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. “I feel that I have a number of good qualities”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. “All in all, I am inclined to feel that I am a failure”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. “I am able to do things as well as most other people”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. “I feel that I do not have much to be proud of”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. “I take a positive attitude toward myself”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. “On the whole, I am satisfied with myself”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. “I wish I could have more respect for myself”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. “I certainly feel useless at times”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. “At times, I think I am no good at all”</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please respond by circling the appropriate number, circle only one number in each section.
Section 8: Listed below are different types of assistance which people sometimes feel helpful. Please answer all the questions. Please circle only one number in each section. How often is each of the following kinds of support available to you, if you need it?

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Someone to talk about things that worry you</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2.</td>
<td>Someone to help take care of your child(ren)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3.</td>
<td>Someone to talk to when you have questions about raising your child(ren)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4.</td>
<td>Someone who will help you financially if you need it</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5.</td>
<td>Someone to encourage or keep you going when things seem hard</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6.</td>
<td>Someone who accepts your child(ren) regardless of how (s)he acts</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7.</td>
<td>Someone to help with household chores</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8.</td>
<td>Someone to relax or a joke with</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9.</td>
<td>Someone to do things with your child(ren)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10.</td>
<td>Someone to provide you or your child(ren) with transportation</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11.</td>
<td>Someone to deal with agencies or organisations when you feel you cannot</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12.</td>
<td>Someone who tells you about services for your child or family</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13.</td>
<td>Do you attend support groups for parents/families</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14.</td>
<td>Do you make use of online support groups for parents / families, e.g., chat rooms, Facebook</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15.</td>
<td>Do you take part in fund raising for any causes</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16.</td>
<td>Do you take part in advocacy (e.g., protests or marches) for any causes</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
### Section 9: This section is about how you feel in general. Read each item and circle the appropriate answer which comes closest to how you have been feeling in the PAST WEEK. Don’t take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

<p>| | | | |</p>
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<th></th>
<th></th>
<th></th>
<th></th>
</tr>
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<td>Most of the time</td>
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<td>Time to time</td>
</tr>
<tr>
<td>2. I still enjoy the things I used to enjoy</td>
<td>Definitely as much</td>
<td>Not quite so much</td>
<td>Only a little</td>
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<tr>
<td>3. I get a sort of frightened feeling as if something awful is about to happen</td>
<td>Very definitely and quite badly</td>
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<td>A little but it doesn’t worry me</td>
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<tr>
<td>4. I can laugh and see the funny side of things</td>
<td>As much as I always could</td>
<td>Not quite as much now</td>
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<td>5. Worrying thoughts go through my mind</td>
<td>A great deal of the time</td>
<td>A lot of the time</td>
<td>From time to time but not too often</td>
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<td>6. I feel cheerful</td>
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<td>7. I can sit at ease and feel relaxed</td>
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<tr>
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<td>I may not take quite as much care</td>
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<tr>
<td>11. I feel restless as if I have to be on the move</td>
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<td>As much as ever I did</td>
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<td>13. I get sudden feelings of panic</td>
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<td>Quite often</td>
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<tr>
<td>14. I can enjoy a good book or radio or TV programme</td>
<td>Often</td>
<td>Sometimes</td>
<td>Not often</td>
</tr>
</tbody>
</table>
Section 10: Physical Health Questionnaire: The following items focus on how you have been feeling physically during the last year and how often it happened.

1 = Not at all    2 = Rarely    3 = Once in a while    4 = Some of the time    5 = Fairly often    6 = Often    7 = All of the time

**Please respond by circling the appropriate number.**

<table>
<thead>
<tr>
<th>In the last year how often...</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. have you had difficulty getting to sleep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>2. have you woken up during the night?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3. have you had nightmares or disturbing dreams?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>4. has your sleep been peaceful and undisturbed?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>5. have you experienced headaches?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>6. did you get a headache when there was a lot of pressure to get things done?</td>
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<td>3</td>
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<td>7</td>
</tr>
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<td>7. did you get a headache when you were frustrated because things were not going the way they should have or when you were annoyed at someone?</td>
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<td>6</td>
<td>7</td>
</tr>
<tr>
<td>8. have you suffered from an upset stomach (indigestion)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>9. did you have to watch what you ate carefully to avoid stomach upsets?</td>
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<td>2</td>
<td>3</td>
<td>4</td>
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<td>6</td>
<td>7</td>
</tr>
<tr>
<td>10. did you feel nauseated (‘sick to the stomach’)?</td>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>11. were you constipated or did you suffer from diarrhoea?</td>
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<td>3</td>
<td>4</td>
<td>5</td>
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<td>7</td>
</tr>
<tr>
<td>12. do you have minor colds? (that made you feel uncomfortable but don’t keep you sick in bed or off work)</td>
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<td>13. have you had respiratory infections more severe than minor colds that “laid you low” (bronchitis, sinusitis)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

1. Have you been to see your G.P. for any of these symptoms?  Yes / No

2. What medication were you prescribed

3. If you suffer from any of the symptoms above, are they related to a diagnosis e.g., my symptoms are related to my gluten intolerance rather than stress.  Yes / No
If they are, please indicate what the diagnosis is

4. Compared to others of your age and sex, how would you rate your general health? (Please circle one)

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Above average</th>
<th>Average</th>
<th>Below average</th>
<th>Very poor</th>
</tr>
</thead>
</table>

Thank You

Thank you so much for completing the questionnaire, your help is invaluable in conducting this study. I realise I have asked you a lot of personal questions and appreciate your co-operation in this research.

Would you be willing to be contacted to take part in similar follow-up research? Follow up surveys will be shorter as demographic information has already been collected here.

If yes, please provide an email address; this email address will be kept separate from any identifying data and will only be used to contact you in the event of follow-up research.
Influence of Psychosocial Factors on the health of parents

STUDY TWO

These questions are about how you feel in general. Read each item and circle the appropriate answer which comes closest to how you have been feeling in the PAST WEEK. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

<table>
<thead>
<tr>
<th>1. I feel tense or wound up</th>
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<th>A lot of the time</th>
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<tr>
<td>2. I still enjoy the things I used to enjoy</td>
<td>Definitely as much</td>
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<tr>
<td>6. I feel cheerful</td>
<td>Not at all</td>
<td>Not often</td>
<td>Sometimes</td>
<td>Most of the time</td>
</tr>
<tr>
<td>7. I can sit at ease and feel relaxed</td>
<td>Definitely</td>
<td>Usually</td>
<td>Not often</td>
<td>Not at all</td>
</tr>
<tr>
<td>8. I feel as if I am slowed down</td>
<td>Nearly all the time</td>
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<td>Quite often</td>
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<td>10. I have lost interest in my appearance</td>
<td>Definitely</td>
<td>I don't take so much care as I should</td>
<td>I may not take quite as much care</td>
<td>I take as much care as ever</td>
</tr>
<tr>
<td>11. I feel restless as if I have to be on the move</td>
<td>Very much indeed</td>
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<td>Often</td>
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<td>Not often</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>
The following items focus on how you have been feeling physically during the last year and how often it happened.

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

Please respond by circling the appropriate number.

**How often...**

1. have you had difficulty getting to sleep?  
   - 1 = Not at all  
   - 2 = Rarely  
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2. have you woken up during the night?  
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3. have you had nightmares or disturbing dreams?  
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   - 2 = Rarely  
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4. has your sleep been peaceful and undisturbed?  
   - 1 = Not at all  
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5. have you experienced headaches?  
   - 1 = Not at all  
   - 2 = Rarely  
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6. did you get a headache when there was a lot of pressure to get things done?  
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   - 1 = Not at all  
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12. do you have minor colds? (that made you feel uncomfortable but don’t keep you sick in bed or off work)  
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    - 1 = Not at all  
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