

Primary Caregivers of Children with Autism Spectrum Disorders – an exploration of the stressors, joys, and parental coping before and after out-of-home placement

By

Michael Kenneth Corman
B.A. University of Victoria, 2004

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Requirements for the Degree of

MASTERS OF ARTS

in the Department of Sociology

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Primary Caregivers of Children with Autism Spectrum Disorders – an exploration of the stressors, joys, and parental coping before and after out-of-home placement

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Abstract

In the present phenomenological study, mothers of children with Autism Spectrum Disorder (ASD) were interviewed using semi-structured, open-ended interview questions. The purpose of this study was to explore the stressors and joys, and parental coping associated with having a child with ASD, before and after out-of-home placement. A total of 9 mothers, six from British Columbia and three from Alberta, participated in the study. The findings suggest that along with stressors, parents experienced a multitude of joys throughout their caregiving experiences. Also, joys had an impact on caregiver's stress-coping process. This study, therefore, expanded upon current states of knowledge on the adaptational function of joys to caregivers of individuals with chronic conditions. In light of the findings, a modified stress-coping process model based on the work of Lazarus and Folkman (1984), Folkman (1997), and Pearlin et al. (1990; 1981) is proposed. Also, findings shed light on mothers' lived-experiences leading up to and after out-of-home placement, illuminating an understudied aspect of caregiving for children with ASD.

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Finally, to *My One and Only Love*. Without your continued support, encouragement, and unconditional love, this work would not have been possible. I dedicate this thesis to you.

Chapter I

Introduction

Leo Kanner (1943) first described the term autism in his study of a group of children who “had failed to develop normal relationships, were upset by changes in their environment and showed abnormalities in speech and language” (cited in Freeman, 1997: 641). The American Psychiatric Association describes the characteristics of autism as impairments in “communication and reciprocal social interaction and restricted repetitive behaviors and interests” (cited in Seltzer et al., 2004: 236). It is now recognized that there is no “all-or nothing form (of autism)” but rather a continuum of severity, known as Autism Spectrum Disorders (ASD) (Smith et. al., 1994).

In the past¹, people with ASD were commonly victims of infanticide, human abuse, neglect, and institutionalization. Now, there is a growing movement towards deinstitutionalization and a more equal status in society through a variety of services, support and interventions aimed at improving the conditions for people with ASD and other disabilities (Boyd, 2002; Harmer et al., 2003; Hudson, 1991). With deinstitutionalization to a more community-centered system of care, children, including those with ASD, are now living at home, thus shifting the burden of care onto families (Chappell and Penning, 2004; Gray, 2002a; Jung-won and Zebrack, 2004; Thompson and Doll, 1982). This evolution of care, combined with the fact that over the past 30 years the prevalence of ASD has increased drastically (Croen et. al, 2002; Wing and Potter, 2002; Yazbak, 2003), indicates a need to study how families cope with the stressors of having a child with ASD.

Stress (what I call stressor-outcomes or outcomes) and stressors (antecedents to stress) can affect individuals' well-being in a variety of ways. Wilkinson and Marmot (2003) have described stressors as arising out of both social and psychological circumstances. In parenting, Westman (2001) described a range of stressors, including extended family or other members of the community, employment, health concerns for their children, schooling, child behaviours, and many more. These stressors have the potential to lead to a variety of outcomes for those experiencing them, including but not

¹ It is impossible to give a more specific date. In addition, some of these abuses are still present today.

exclusively low self-esteem, increased anxiety, social isolation, and the inability to cope – all of which impacts an individual’s overall health.

The stress-process model is a conceptual framework that looks at the stressors associated with caregiving; the model focuses on the many related relationships, and the developing and changing nature of these relationships over time, eventually leading to stressor-outcomes (Pearlin et. al., 1990). This model of stress allows for the investigation of how conditions develop and are interrelated to each other. One way of dealing with stressors and stressor-outcomes is to use a variety of resources and strategies that act as buffers against them. Lazarus and Folkman (1984) describe coping as a shifting process that varies depending on the stressful encounter or experience, allowing for individuals to mediate the effects of stressor-outcomes on their well-being (Kelso et al., 2005) by managing both internal and external demands (stressors) that are appraised as taxing (Lazarus and Folkman, 1984 cited in Kelso et al., 2005: 3; Folkman and Moskowitz, 2004). Folkman (1997) describes coping as consisting of five different resources: social support networks, utilitarian resources, general and specific beliefs, problem-solving skills, and an individual’s health, energy, and morale. There are at least two types of strategies: emotion-focused and problem-focused coping (Kelso et al., 2005; Opperman and Alant, 2003).

Most current research in the field of ASD focuses on the medical and psychological characteristics of the disability (Pruchno, 2003; Wing and Potter, 2002). The research that does focus on how parents cope with the stressors of having a child with ASD is limited, with a primary focus on children who are able to live at home (Glasberg, 2000; Gray, 1994; Smith et al, 1994). In some cases however, the condition of the child’s ASD is too severe for parents to cope, ultimately leading to out-of-home placement (Gray, 2002a). Because there is a lack of research on this specific and unique population, there is a need to explore how families cope with the stressors of having a child with ASD who is eventually placed outside of the home. For the purposes of this study, out-of-home placement refers to foster-care, residential homes, or residential treatment-care facilities, hereafter “placement” or “placed”.

Furthermore, most caregiving research on parenting children with disabilities has only provided a one-dimensional view, with a main focus on the negative factors

associated with caregiving (McCallion and Toseland, 1993). This limitation is also evident in the broader study of caregiving. Chappell et al. (2003: 367) explain, “The focus on the negative aspects of caregiving, specifically stress and burden, has been concomitant with a lack of attention to the positive or more satisfying aspects of the caregiving situation”. This limited focus offers only partial insights into the experiences of caregiving for children with chronic conditions. Because of this limited focus, there is a need for research to examine the other side of the spectrum, the positive and joyous side of parenting children with disabilities.

Anne-Marie Ambert (1992) describes parental gratification as an experience of joy, derived from a child’s actions, that creates a sense of personal pleasure for parents. Such experiences vary from parent to parent, but all parents are “expected to derive satisfaction from their [parental] role” (Ambert, 1992: 248). Current conceptualizations of the stress-coping process offered by both Lazarus and Folkman (1984) and more recently Folkman (1997), and the stress-process model of Pearlin et al. (1990; 1981) have failed to address positives, what I call joys of caregiving, in a systematic way. For instance, Folkman and Lazarus’s coping process model can be criticized for failing to account for the positive and joyous experiences of parenting children with disabilities (Kelso et al., 2005: 3). This criticism also applies to Pearlin et al’s (1990) stress-process model, which is based on the definition of stress as taxing (negatively) for an individual. In order to gain a more complete understanding of caregiving for children with disabilities, specifically ASD, it is important to account for both the joyous and stressful experiences of caregiving, in addition to coping strategies and resources utilized throughout the caregiving experience.

A re-orientation in inquiry is needed that offers a more complete understanding of the lived-experiences of parenting children with ASD, and the broader study of caregiving and stress. Despite the shortcomings of these models, the coping process model of Folkman and Lazarus does allow for a scope that looks beyond adjustment and toward positives, thereby forcing attention to both the stressors and joys of caregiving (Kelso et al., 2005). However, as Steven Best writes, “no single theory or method of interpretation by itself can grasp the plurality of discourses, institutions, and modes of power that constitute modern society” (Best, 1995: 93). It is through a dialogical

relationship, where theories and discourses are combined to offer greater insight and a more complete understanding of the social, that it becomes possible for what Best (1995) calls a multiperspectival vision. This type of vision is ideal when exploring and trying to gain a better understanding of parents' lived-experiences of caregiving for children with ASD, before and after placement. As such, Pearlin et al's (1990) stress-process model can provide useful insights into the sociological aspects of stress that can benefit the stress-coping process model (or transactional model) of Lazarus and Folkman. These models, as well as additional conceptual insights, can be combined to create a modified stress-coping process model that focuses on the stressors and joys of caregiving directly related to the caregiving role and external to it. In so doing, a more complete understanding of parents' lived-experiences will emerge. It is from this framework that I intend to explore the stressors, joys and parental coping experienced by parents of children with ASD before and after placement.

Purpose Statement:

The purpose of this study is two-fold. First, this study intends to explore the lived-experiences of mothers who caregive for children with ASD who are eventually placed, by focusing on the stressors and joys of caregiving. This will serve to expand the current research on ASD, which primarily focuses on the stressors and negative aspects associated with parenting children with disabilities, and the live-at-home population of children with developmental disabilities. By bringing attention to the joys of parenting children with disabilities, this study intends to inform stress and coping research and offer a more complete understanding of the experiences of caregiving for children with ASD.

Second, by systematically investigating caregivers' lived-experiences before and after placement, this study will allow for an exploration and greater understanding of the stressors and joys, before and after placement has occurred (the decision to place being the point where the parents no longer perceive themselves as being able to cope) as well as a greater understanding of parental coping during these times. This will provide a better understanding of the factors associated with placement. In addition, this study does not solely identify the stressors and joys of caregiving for a child with ASD, but provides

an in-depth analysis of the nature of stressors and joys based on the lived-experiences of mothers.

This study focuses solely on the experiences of mothers who are primary caregivers and are potentially and conceptually likely to experience severe distress. If positives occur both within and outside of the stress-coping process for this specific population of caregivers, it can be assumed that positives occur for other less stressed populations of caregivers. It is for this and many other reasons as discussed above that joys, as well as stressors, should be explored both within and outside of the caregiving process. By exploring the lived-experiences of these mothers, more will be learned about the joys of caregiving internally associated with the caregiving experience and those external to it.

Layout of chapters:

In Chapter II, I begin with a review of three different conceptualizations of stress: the stimulus response model, the stress-coping process model or transactional model of stress (Lazarus and Folkman, 1984), and the stress-process model (Pearlin et al., 1990; 1981). The latter two models theoretically frame this inquiry. I discuss a modified stress-coping process model that integrates the insights of the stress-process model offered by Leonard Pearlin and colleagues, and the transactional model of stress offered by Richard Lazarus and Susan Folkman. As will be discussed, this modified conceptualization tries to compensate for limitations in stress-coping research and caregiving for individuals with ASD. In Chapter II, I also describe past research on caregiving for individuals with ASD. This section focuses on the stressors, negative outcomes, coping strategies and resources including social supports, the joys of caregiving, and placement of individuals with disabilities. For clarity, I end this chapter with a list and definition of terms as they are used in this study.

In Chapter III, I provide a detailed account of the research design and methodology employed in this study. The findings of this thesis are reported in Chapter IV. This chapter begins with a brief descriptive overview of the mothers who participated in this study. The remainder of this chapter is organized into six sections based on themes discussed in the conceptual framework (Chapter II) and themes that emerged from the

participants themselves. The first five sections are divided into five distinct yet overlapping time periods. These sections report on the years prior to placement, leading up to placement (leading up to parents' appraised inability to cope and the time leading up to their child leaving the home), and after placement (the stressor-period immediately following placement and the time "after the dust settled"). These sections focus on the stressors and their outcomes, joys, and how parents coped during the respective periods. Section six of chapter IV reports on mothers' reflections of their overall experience of caregiving.

This thesis concludes with Chapter V. The first part discusses the findings of this study in relation to the current state of knowledge on caregiving for children with ASD. The next two parts discuss the theoretical and practical implications of this study. The fourth part introduces other issues that have surfaced from this study. I conclude this thesis with a discussion of the limitations of this study and future areas of research.

Chapter II

Review of Literature

A review of current and past research on stress, coping, and caregiving provides a useful avenue to situate and frame this exploratory study. This purpose is consistent with procedures outlined in transcendental phenomenology (Moerer-Urdahl and Creswell, 2004; Moustakas, 1994), the primary methodological approach used here. However, this review of literature is not intended to “constrain the views of participants” (Creswell, 2003: 46) but to contextualize and provide a rationale for the focus (Rudestam and Newton, 2001). This is further discussed in chapter III.

The concept of stress has been around since the early 1940s, and the idea even longer. Despite the longevity of the term and the vast amount of research it has generated, the semantics of the term “stress” and the way it is conceptualized varies from person to person and across disciplines (see McCubbin et al., 1982; Selye, 1956; Wilson, 1983). These inconsistencies are most likely due to the complex nature of stress. Hobfoll (1988: 2) explains,

[Stress] involves all the systems of the body – cardiovascular, endocrine, and neurological; all the systems of the psyche – cognitive, emotional, and unconscious, and occurs in all social systems – interpersonal, intrapersonal, small group, large group, and societal...It involves our loves, hates, closest attachments, competition, achievement – indeed every matter in which humans are involved.

In addition, the interdisciplinary study of stress led Richard Lazarus (1966: 27) to write, “thus we can speak of the field of stress and mean the physiological, sociological, and psychological phenomena and their respective concepts” (cited in McCubbin et al., 1982: xii). Therefore, this chapter begins with a brief snapshot of three different yet overlapping conceptualizations of stress.

The first conceptualization can be called the stimulus-response model of stress (Selye, 1956). It was followed by two more recent theoretical models of stress: the transactional model of stress (Lazarus and Folkman, 1984), and the stress-process model (Pearlin et al., 1990). The latter two models reflect current thinking in the area (Hobfoll, 1988). While these two models overlap considerably, specifically in their definitions of stressors and stress, they differ in their focus on appraisal processes and the social aspects of stress. While I focus on these models, it is important to note that these are not the only

models that exist². In fact there are multiple models; to review each is outside the scope of this chapter (see Grimshaw, 1999). Following a description of these models and some critiques, I describe a modified conceptualization that I believe will offer a better understanding of caregivers' lived-experiences. This modified version of these two models is used in this inquiry.

This chapter, then, provides a review of literature on caregiving for children with ASD. I focus on the stressors (antecedents to stress) and stressor-outcomes experienced by parents, followed by an examination of parental coping and social supports. I will then discuss the joys of caregiving followed by a brief review of literature on out-of-home placement for individuals with disabilities. I end this chapter with a section outlining the definition of terms as they are used in this inquiry.

A “stressful” snapshot

Stimulus-response model of stress:

The stimulus-response model of stress was originally developed by Selye and others (W. B Cannon and Adolf Meyer, cited in Kaplan, 1983). It “asserts that stress is the physiological reaction of the body to life situations that can be both happy events or unhappy events” (Selye 1974, cited in Schopler and Mesibov, 1994: 178). This model of stress and the research that followed from it attempted to objectively measure stress, the rate of wear and tear in the body (Selye 1956: 3), through measurable reactions of the body to environmental demands, such as during times of war, and workforce demands (Levi, 1967). According to this model, stressors (stimuli that led to a stressful response) were inherently dangerous/negative. Levi (1967: 34) explains:

What they (stimuli) all represent is an excess or a deficiency of influences to which the body is normally exposed (such as oxygen, nutrition, warmth, air pressure, irradiation) or else the introduction of something new and foreign (such as certain bacteria and viruses, poisons, accidents).

² Based on my initial reading of the literature on caregiving for children with autism and other developmental disabilities, these two models seemed most suitable for this type of research because they provide useful insights into the psychosocial study of stress and caregiving; allowed a scope to focus on the joys of caregiving; allowed for a focus on caregiving from the perspective of those who experienced stress; and were suitable for qualitative methods.

This stimulus-response process, activated by noxious stimuli (stressor(s)), would result in the bodily response that produced hormones from the pituitary and adrenal glands “that stimulate the body’s protective functions” in an attempt to reinstate equilibrium (Palmer, 1981: 15). In more colloquial terms, as a result of these stressors, a person’s bodily equilibrium would be “upset”. If the body is able to cope, it returns to a normal state of equilibrium. If the problem persists, exhaustion can be experienced and other ill effects might result.

By focusing on the physiological response of the body to demanding changes in a person’s environment, research of this type primarily focused on how the sympathetic and parasympathetic systems, in combination with endocrine glands, react under stressful conditions. The sympathetic system is responsible for “accelerat[ing] the activity of the heart and the lungs but inhibits the digestive organs” while the parasympathetic system “inhibit[s] the heart and lungs but stimulates the digestive system” (Levi, 1967: 28). Research explored how these systems continually interacted in an attempt to stay in equilibrium and therefore allow the body to adjust to demanding life events. (For further discussion, see Levi, 1967: 30; Selye, 1956).

According to this model of stress, in order to cope with the demands of a person’s environment, a “plan of defense” known as the General Adaptation Syndrome (GAS) (Levi, 1967: 35) occurs. GAS consists of three phases of “stress reactions”: 1) alarm reaction; 2) stage of resistance; and 3) stage of exhaustion. Stage one can be thought of as a “generalized call to arms of the defensive forces in the organism” (ibid. 31). Through his experiments, Selye found that continued exposure to stress-causing agents elicited an alarm reaction that either killed the organism, or resulted in resistance or adaptation to that agent. This resistance or adaptation represents stage two of GAS. Lastly, if continuously exposed to the stress-causing agent, the resistance/ adaptation seen in stage two was eventually lost, resulting in a stage of exhaustion. (For further discussion, see Selye, 1956: 31).

Critiques of this model are numerous. For instance, while the above stressors are physical in nature, involving physiological responses as described above. However, psychological processes are also involved (Levi, 1967). Yet these psychological processes are given scant attention, conceptually or empirically. In other words, by

focusing primarily on the physiological responses of the body to noxious stimuli, this model of stress is not interested in the psychological or emotional side of the stress reactions (Hobfoll, 1988). Furthermore, Grimshaw (1999) suggests that this approach is limited in its ability to distinguish between those stressors that cause stress and those that do not. Most importantly, from a sociological lens, this approach does not allow for “individual difference in the way people respond to stress factors....ignor[ing] the interactions between the person and their various environments” (Grimshaw, 1999: 34-35). Such confines, with a focus on the physiological reactions of the body to stress, limit the relevance of this model today, as there is a shift in thinking towards the psychosocial aspects of stress (Hobfoll, 1988: 6).

While the stimulus-response model is primarily interested in the stressor and a person’s physiological response process under stressful conditions, the next two models discussed are interested in what occurs between stressor and response to stress as they relate to transactions between person and environment; they focus specifically on a person’s psychological appraisal processes (Lazarus and Folkman, 1984; Folkman, 1997; Lazarus, 1966) and how sociological conditions arise and come to be related to each other in the stress-process (Pearlin et al., 1990; 1981).

Transactional Model of Stress – the stress-coping process

The 1960s began with “a great leap forward” in the conceptualization of stress with the research of Speilberger (1966) and Lazarus (1966). While the stimulus-response approach to stress focused on physiological responses to stressful stimuli, Speilberger conceptually provided a way of understanding stress in relation to personality traits of individuals. According to one stress researcher, “Speilberger saw a differential psychological reaction from persons whose personality traits differed” (Hobfoll, 1988: 8). Although this illuminated aspects of cognition in the stress process, it was Lazarus (1966), and later Lazarus and Folkman (1984), who focused on stress and coping as a process that brought a person’s appraisal into the equation. This shift in conceptualization purported that while all individuals experience multiple stressors throughout their everyday lives, it is how stressors are appraised that leads to an event being stressful or not, which further activates coping processes to mediate the impacts of stressors and

stressor outcomes. In other words, depending on how one appraises an event and their personal resources, the experience of stress differs from individual to individual (Lazarus and Folkman, 1984).

This model of stress and coping is depicted in Figure 2.1. It begins with a stressor, which is defined as an antecedent to an event that has the potential to cause stress (stressor outcomes). It is through two axes of appraisal, primary appraisal and secondary appraisal, that an event is experienced as stressful or not and that determines what coping strategies and resources are utilized (Lazarus, 1966). Accordingly, primary appraisal or cognitive appraisal determines whether an event is appraised as being “irrelevant”, “benign-positive”, or a threat and thus “event stressful”. Once appraised as stressful, further appraisal may result where one views the situation as harmful, threatening, or challenging (Grimshaw, 1999). If the event is appraised as stressful, coping strategies and resources are appraised (secondary appraisal) in an attempt to deal with the stressful event (Lazarus, 1966). In other words, the former determines whether stress is experienced and the latter activates coping strategies and resources depending on the primary appraisal of the event.

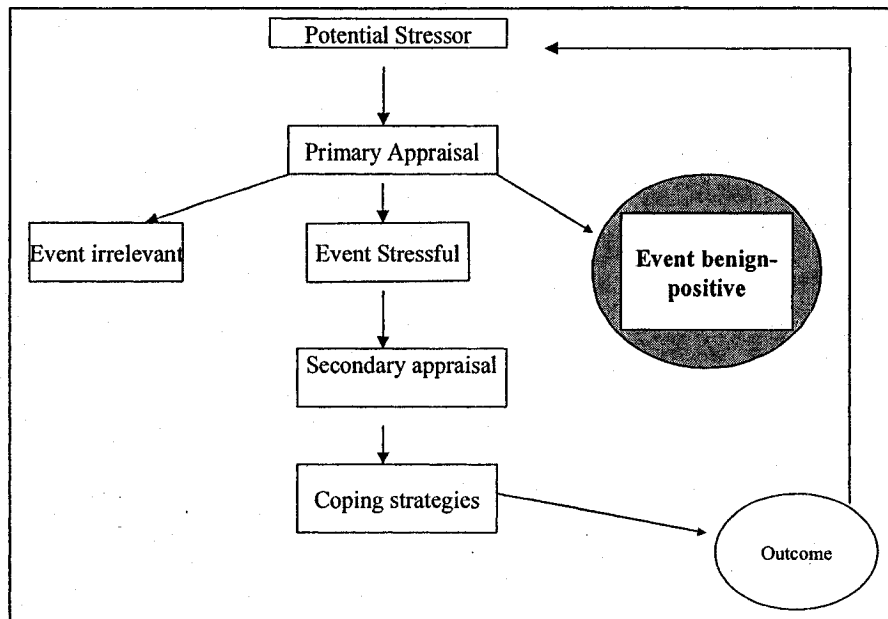
Coping in this model refers to constantly changing behavioural or cognitive efforts that are made when either internal or external demands are appraised as taxing on an individual’s personal resources (Folkman and Moskowitz, 2004; Lazarus and Folkman, 1984). Coping is separated into two domains, coping resources and strategies. Quine and Pahl (1991: 59) explain coping resources:

They may be physical, material, social, psychological or intellectual...Folkman and Lazarus [and Schaefer] (1979) outline five categories of coping resources including *utilitarian resources*, e.g., socio-economic status, money, available services; *health, energy, or morale*, e.g., depression, pre-existing physical and psychiatric illness; *social networks*, e.g., close interpersonal relationships; *general and specific beliefs*, e.g., self-efficacy, mastery, self-esteem; and *problem solving skills*, e.g., intellectual skills, cognitive flexibility and complexity and analytic ability which enable people to formulate alternative courses of action.

Coping strategies are separated into problem-focused and emotion-focused coping. The former refers to active behavioural efforts to mediate stress by managing or changing the stressor(s) causing the problem, and the latter refers to cognitive efforts used for

controlling and regulating emotional responses to the event (Folkman and Lazarus, 1980; Kelso et al., 2005; Slavin et al., 1991: 158).

Figure 2.1 - Lazarus and Folkman (1984) Transactional Model of Stress and Coping



Source: Cited in Kelso et al., 2005

It is important to note that the “event stressful” activates “stress reactions” which are “reflections or consequences of coping processes intended to reduce threat”. Primary and secondary appraisals therefore overlap in time (Lazarus, 1966: 152-159). Depending on this stress-coping process, three primary outcomes can occur, including negative affects such as fear, anger, depression, guilt, etc; behavioural reactions; and “alterations of adaptive functioning” (Lazarus, 1966: 319).

Differing significantly from the stimulus-response model, Lazarus and Folkman (1984) describe a more current definition of stress as a relationship between person and environment, where individual characteristics and specific environmental factors are taken into consideration, such that individuals are impacted differently depending on how they appraise a situation. An event is therefore stressful to an individual when she cognitively appraises it to be stressful, and thus “taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus and Folkman, 1984: 21). While Lazarus,

Folkman, and others illuminated the psychological aspects of the stress-process through their focus on appraisal processes and coping, this model fails to address the more sociological aspects involved in a person's stress-process. Pearlin et al's (1990; 1981) stress-process model provides theoretical insights into these more sociological processes that are involved in a person's stress-coping process. A discussion of this model follows.

Stress Process Model

Arising mainly from the work of sociologists and in response to the stimulus-response model of stress, Pearlin and colleagues suggest that it is not only the failure to reestablish equilibrium that creates stress but that broader societal implications exist, where a person's role and structural aspects that organize that role must be taken into consideration (Kaplan, 1983: 4). Pearlin explains:

What I find worrisome [about stress research] is that we may be directing inordinate energies toward finding the conditions that prevent or buffer stress without being commensurately energetic about learning how stress arises in the first place (cited in Kaplan, 1983: 3).

The stress-process model therefore arose out of the perceived lack of focus on the social origins of stress (Pearlin, cited in Kaplan, 1983). This model attempts to provide a conceptualization of stress that does not stem from "unaccounted happenings" outside the purview of societal forces (Pearlin, 1989: 249).

Pearlin emphasizes that life events do not simply cause stress. Rather the quality of the event determines whether or not stress will result (Kaplan, 1983). While he suggests that this is a major step in conceptualizing life events research on stress (Pearlin et al., 1981), he went on to explain that it is not just the nature of the event that causes role strain, but rather it is the subjective evaluations of events, in combination with the more objective properties, that lead to strain (Kaplan, 1983). However, Pearlin (1983) also critiques the transactional study of stress for failing to draw attention to how institutions and social patterns affect people (cited in Hobfoll, 1988: 87). Incorporating sociological insights into the stress-process, Pearlin and colleagues provide a rationale and a way to explore how social forces impact individuals' roles throughout the life course and the stress they experience (Kaplan, 1983).

The stress-process model is a conceptual framework of stress that focuses on the many interrelationships between stressors, mediators of stress, and manifestations of stress (Pearlin et al., 1981: 337). This model does not simply focus on one of these domains, but combines these three separate, though overlapping and linking domains in what has become known as the stress process (Pearlin et al., 1990; 1981). In focusing on the developing and changing nature of these relationships over time (Pearlin et al., 1990), this model allows for the investigation of how conditions arise and come to be related to each other. Furthermore, this model pays attention to a multitude of social variables within and outside of the stress-coping process connected to personal stress.

As caregiving “is potentially a fertile ground for persistent stress” (Pearlin et al., 1990: 583), in addition to joys as discussed later, what follows is an explanation of this model of stress utilizing Pearlin and colleagues research on caregiving. Figure 2.2 represents the stress-process model. This model begins with the background and context of individuals who might be experiencing stress. In describing the background and context of caregivers, this component of the model focuses on characteristics of the caregiver, including socio-economic status, age, gender, etc, because conceptually and empirically they are intertwined throughout the entire stress process (Pearlin et al., 1990).

The kinds and intensities of stressors to which people are exposed, the personal and social resources available to deal with the stressors, and the ways stress is expressed are all subject to the effects of these statuses. (Pearlin et al., 1990: 585)

Pearlin and colleagues point out that while caregivers might seem cut off from wider societal relations, these relations very much influence a person’s stress-process (Ibid) (discussed below). This is seen in their conceptual usage of external stressors – those outside the direct caregiving experience – such as family conflict, economic problems, access to resources and formal and informal supports. These external forces directly relate to a person’s stress-process (Pearlin et al., 1990). This is discussed below.

Whereas Lazarus and Folkman describe primary and secondary *appraisals*, Pearlin et al. (1990) distinguish between primary and secondary *stressors*, which comprise the heart of the stress-process. It is important to note that the terms primary and secondary stressors do not refer to the severity or significance of stressors (i.e. one stressor being more stressful than the other). The point is that interrelated stressors

emerge as caregivers are immersed in providing long-term care (Ibid, 587). Primary stressors derive directly from the care provided, and the nature and magnitude of this care (Ibid, 586-587). In their research on Alzheimer's patients, the cognitive status of the care receiver as well as problematic behaviours are given as examples of primary stressors that impact a caregiver's stress process. These primary stressors can lead to secondary stressors external to (outside of) the direct caregiving role, but are directly associated with a persons' stress-process. Pearlin et al., (1990: 587) explain,

It is almost axiomatic that serious stressors (primary stressors), especially those that are chronic, generate other stressors. We conceive of the demands of caregiving as encompassing primary stressors that in turn lead to other problems and hardships, which we refer to as secondary.

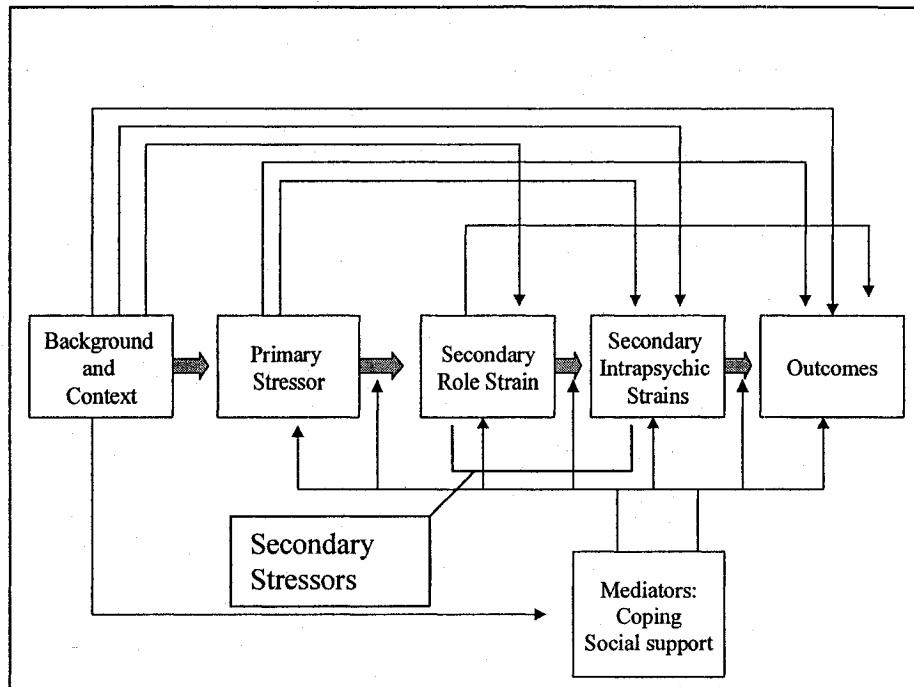
The conceptualization of secondary stressors in this model allows for a greater and broader understanding of external forces outside of the direct caregiving experience and how these forces impact caregivers' stress-process. This conceptualization therefore reveals the dynamic character of caregiver stress (Ibid, 589). These stressors are separated into two types: role strains, which derive from activities outside the direct caregiving role (Ibid, 588); and intrapsychic strains, which involve the psychological dimensions such as mastery, self-esteem, loss of self, etc.

Pearlin defines role strains as the "hardships, challenges, and conflicts or other problems that people come to experience as they engage over time in normal social roles" (cited in Kaplan, 1983: 8). Such roles have the potential to act as stressors, which impact a person's stress-process³. The focus on these secondary stressors and their role in the stress-process, Pearlin suggests, "should bring the part played by life events in the stress process into a more balanced and interesting perspective" (Ibid: 4-5). Pearlin's intent is therefore to bring stress research more in line with the structure of experience that constitutes people's everyday lives (Ibid.).

³ Pearlin identifies six types of role strain. These are:

1) Those involving problems between the individual and the nature of the tasks she or he is expected to perform; 2) interpersonal problems within role sets; 3) intrapersonal problems resulting from participation in multiple role sets; 4) role captivity; 5) the gain and loss of roles; and 6) the restructuring and change of roles within role sets (for further discussion see Kaplan, 1983: 8-30).

Figure 2.2 - The Stress-process Model



Source: Pearlin et al., 1990

Within this model, coping and social supports are conceptualized as mediating variables such as behaviours, perceptions, and cognitions (Pearlin et al., 1981), which govern the relationship between stressors and stressor outcomes. This is similar to other conceptualizations in psychosocial stress research (Pearlin et al., 1990). For instance, similar to the concept of emotion-focused and problem-focused coping outlined by Lazarus and Folkman (1984), coping for Pearlin refers to actions taken by individuals on their own behalf to mediate the effects of stress by either avoiding, mediating the meaning of the situation, or lessening the impacts of the stressor (Pearlin et al., 1990) (see Lazarus and Folkman, 1984: 150 for similarities). These personal actions are based on an individual's psychological resources (Pearlin and Schooler, 1978). Pearlin (1989: 250) goes on to explain why coping is of sociological interest:

Although coping refers to individuals' actions and perceptions, it is of sociological interest because important elements of coping may be learned from one's membership and reference groups in the same ways as other behaviors are learned and internalized.

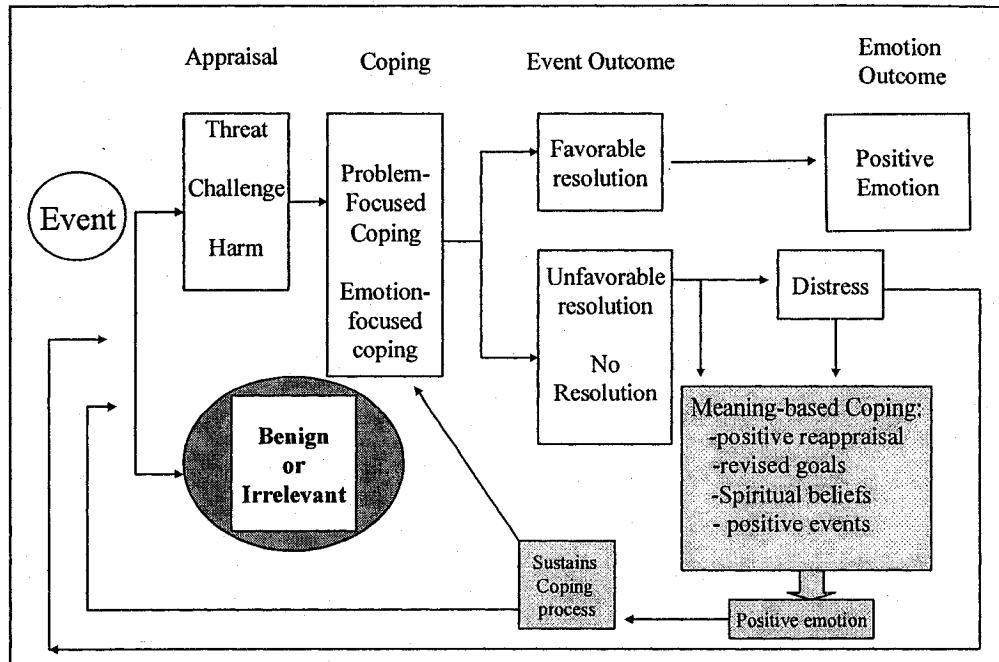
Furthermore, similar to the concept of coping resources for Lazarus and Folkman (1984), Pearlin (1989) focuses on social supports as a mediator of the stress process, where social support is the actual resource a person utilizes from their social network, such as family, friends, colleagues, etc (Pearlin and Schooler, 1978; for further discussion, see Pearlin et al., 1996). Stress outcomes conceptualized in this model are similar to other outcomes represented in other models and include depression, anxiety, guilt, physical and cognitive problems, etc. (for further discussion, see Pearlin et al., 1981).

A Critique of the Stress-process and Transactional Models of Stress

Research has traditionally focused on the negatives throughout caregivers' lived-experiences (Carmen, 2003; Diener, 1984; Johoda, 1958, cited in Ryff, 1989). This focus is particularly evident in the original stress-coping model offered by Lazarus and Folkman (1984), in which the stress-coping process occurs within a vacuum of negativity, devoid of the social. As such, benign or positive events have no impact (see Figure 2.3). Such a singular view fails to account for other important dimensions (Grant et al., 1998). Making up for some of the limitations of the transactional model of stress, Pearlin et al's (1990) stress-process model provides a greater understanding of how societal forces impact people's experiences of stress. However, the same critique (the focus on the negatives) applies to the stress-process model.

Research on caregiving has only recently considered gratification and the role of positive factors in the stress-coping process of caregiving (Folkman and Moskowitz, 2000; Grant et al, 1998). Schwartz (2003: 576) defines caregiver gratification as consisting of psychological and emotional rewards that a person perceives from their caregiving role. I call this the joys of caregiving. This new conceptualization of positive factors is illustrated in Figure 2.3.

Figure 2.3 - Modified model of Coping, Accounting for *Positive Psychological States*



Source: Folkman (1997)

In her study of caregiving for men with HIV/AIDS, Susan Folkman (1997) discussed how positive states can co-occur with negative states. Her findings suggest that “despite high levels of distress, people also experience positive psychological states during caregiving and bereavement” (Folkman, 1997: 1207; Folkman and Moskowitz, 2004). Folkman (1997: 1212) described four positive psychological states associated with coping: 1) positive reappraisal, 2) goal-directed problem-focused coping, 3) spiritual beliefs and practices, and 4) the infusion of ordinary events with positive meaning. All four processes have one underlying characteristic, the appraisal of positive meanings occur *within a stressful event*, known as meaning-based coping. Folkman argues that this meaning-based coping impacts the entire stress-coping process from the time the event is appraised to event outcome.

As already illustrated, positive and negative experiences can co-exist within a particular event appraised as stressful. In addition, the same event or experience may be perceived by one parental caregiver as difficult, and by another as joyous. This difference supports the contextual/transactional model of stress and coping offered by Lazarus and

Folkman (1984). With the recognition of joys (and their adaptational function within the stress-coping process of positive emotion), there has been a significant shift in conceptualizing the stress-coping process to provide for a more complete picture of caregiving experiences.

Despite the inclusion of positive states, it is important to note that within this modified stress-coping model offered by Folkman (1997) and others (Folkman and Moskowitz, 2004; 2000ab; Grant et al., 1998), these states only occur within the stress-coping process. It is limiting to focus only on the positive states that arise within the stress-coping process (with a focus primarily on positive emotions and event outcome). There is a difference between the co-occurrence of stressors and joys within the stress-coping process, and joys that may occur outside the process that might affect caregivers' experiences. This difference reveals a major limitation of the current conceptualization of the stress-coping process; it suggests that positive states outside of the stress-process are benign or irrelevant (see Figure 2.3), possibly not even occurring. When applied to caregiving for children with ASD, this conceptualization suggests that caregiving for children with chronic conditions is inherently stressful where positive states occur only within a stressful situation. This conceptualization does not account for the part of the joys of caregiving that may occur outside of the stress-coping process.

In order to move beyond the limited vision of caregiving inherent in this modified stress-coping model and expand upon this relatively uncharted territory of caregiving (Grant et al., 1998), a theoretical model or framework is needed that conceptually provides for a greater understanding of the overall experience of caregiving for children with chronic conditions. This model should also allow for the expression of experiences both inside and outside of the stress-coping process.

Towards a new conceptualization of the stress-coping process

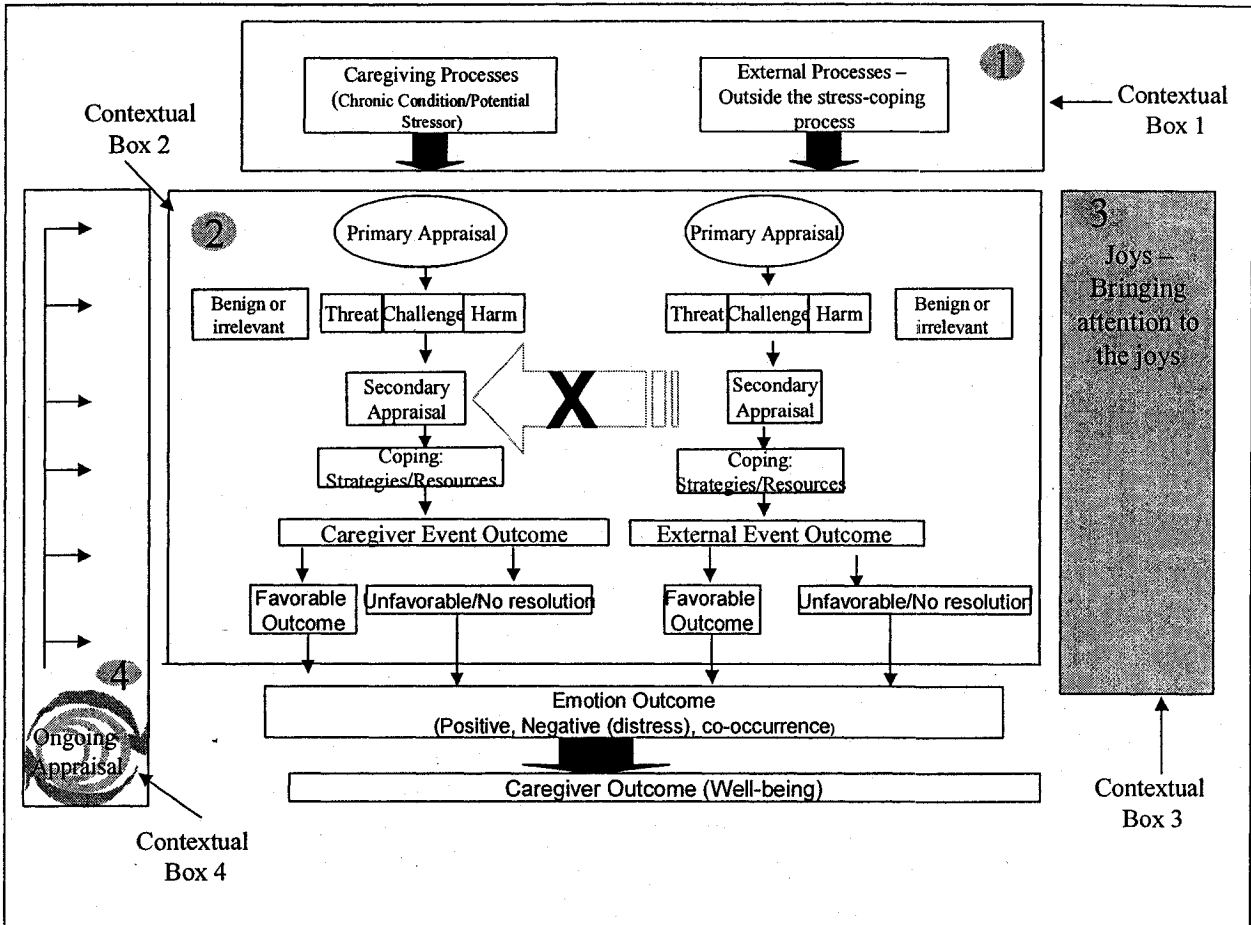
Whether the experience of rewards and gratifications [joys] mediate stress, and the precise ways in which specific stressors and rewards may be connected, represent fertile grounds for further research... There is much to do in explaining variation in rewards and stresses, and in linking these into coping models which can be applied over the family life-course. (Grant et al., 1998: 59; 69)

In response to the limitations mentioned above, I propose a modified theoretical model, depicted in Figure 2.4. The purpose of illustrating this model is to depict a more multiperspectival framework that orients this inquiry. I have no intention of testing this model but intend to gain insight into it. In other words, by conducting this research, the goal is to gain a better understanding of caregivers' lived-experiences, which, inevitably, should shed light on this modified theoretical model.

This model is based on and attempts to blend some of the theoretical underpinnings offered by Pearlin et al. (1990), Lazarus and Folkman (1984), and Folkman (1997) in order to provide a more multiperspectival vision of caregiving for children with ASD. More specifically, this model incorporates Pearlin et al's (1990) conceptualization of primary and secondary stressors, and is therefore separated into two distinct, yet overlapping and interacting processes (illustrated in the contextual box (1)). The left side of this model incorporates Pearlin et al's (1990) primary stressors, which I call "internal processes". These stressors are directly related to caregiving. The right side of this model incorporates Pearlin et al's (1990) conceptualization of secondary stressors; stressors that are experienced outside of the direct caregiving role, which I term "external processes". Although these processes refer to events that occur outside of the direct caregiving role, they are part of the overall caregiving experience and thus impact the stress-coping process and caregiver outcomes.

Both sides of this model utilize key understandings of the stress-coping process offered by Lazarus (1966), Lazarus and Folkman (1984), and Folkman (1997) where a person's appraisals of events impact their experience of stressors and stressor-outcomes (represented in the contextual box (2)). For instance, primary appraisal occurs when a stressor is appraised as taxing on the caregiver, leading to a stressful event. Secondary appraisal occurs when coping resources and strategies are assessed and utilized, impacting caregiver outcome. If an event outcome is favorable, then the person successfully copes, which refers to the conclusion of coping activity (Folkman, 1997: 1216) and absence of pathology (Kelso et al., 2005) (see also Foster et al., 1998). If event outcome is unfavorable or there is no resolution, then distress occurs. Also, positive meaning can be attached to a stressful event or distress results (Folkman, 1997: 1215), impacting caregiver outcome. This process occurs at both the internal and external level.

Figure 2.4 – A modified theoretical model:



It is important to note that the direction of the arrow in the middle of figure 2.4 is bi-directional; the specified direction shown is intended to highlight this study's focus on exploring the stressors and joys both within and outside of the stress-coping process. The intent is to provide for a broader and more complete view of caregivers' lived-experiences.

Differing from current conceptualizations, I introduce the term *joys of caregiving* to exemplify this study's intent to give equal attention to joys and stressors when exploring caregivers' lived-experiences (represented in contextual box (3)). I am not presupposing how joys factor into parents' lived-experiences but am simply emphasizing this study's intention to focus equally on the joys and stressors. Furthermore, I am not limiting joys to the conceptual confines of only stemming from a stressful event (Folkman and Moskowitz, 2000; Folkman, 1997; Schwartz, 2003). This model expresses

how the positives may occur both within and outside of the direct caregiving role. This concept will be explored through interviews with participants.

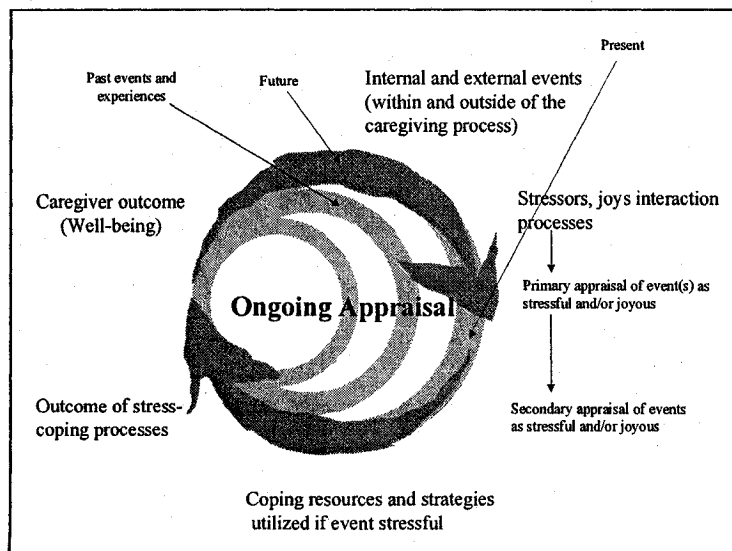
The theoretical conceptualizations that guide this inquiry suggest that stress and coping processes are essentially dynamic and ongoing (Grimshaw, 1999: 4; Slavin et al., 1991: 158; Stein et al., 1997: 873). For instance, Lazarus and Folkman (1984) explain how processes of appraisal and coping are continually influenced by each other. This further engenders new appraisal or reappraisal processes and coping processes throughout encounters. While it might be recognized that these models are tacitly not static in nature, I suggest that in both theory and practice, they do not account for the dynamic nature of caregivers' lived-experiences. By not adequately addressing or conceptualizing this aspect of caregivers' lived-experiences, a limited understanding and account of stressors, joys, and coping involved in caregiving is provided.

The concept of ongoing appraisal was developed in an attempt to tackle this limitation. This concept attempts to provide for a more dynamic account of the interaction between a mother's stress-coping processes and her environment. It is important to first situate this concept. The concept of ongoing appraisal was initially conceptualized from my own experience of caregiving for children with ASD. As I read the literature on caregiving for children with ASD, in addition to noticing a lack of focus on the positive aspects involved in the caregiving process, I was perplexed by what I saw as a static representation of stress-coping processes for caregivers. Second, in readings on institutional ethnography, Smith (2005: 64) uses the term *ongoing social historical processes* in recognizing the social as happening. She writes, "each moment of action is conditioned by what is historically given and reshapes the already given in moving into the future" (Smith, 2005: 70). This description of ongoing historical processes is used in the context of institutional ethnography in describing how the social ongoingly coordinates and organizes people's everyday doings. I borrow and modify this concept to apply it within stress-coping research in an attempt to break away from the static representation of stress and coping processes. It is yet to be determined whether this conceptualization will be supported empirically. Because of the lack of conceptualization and focus in research to date, the concept of ongoing appraisal was developed rationally

rather than empirically (see Rudestam and Newton, 2001: 24 for the distinction between rational and empirical ways of acquiring knowledge).

The concept of ongoing appraisal is illustrated in Figure 2.4 in contextual box (4) and magnified in Figure 2.5. Using the conceptualization of the stress-coping process offered by Lazarus and Folkman (1984) and the stress-process offered by Pearlin et al. (1990), this concept suggests that past events both internal and external of the stress-coping process interact with and impact present and future appraisal processes and outcomes. In other words, people ongoingly assess their situations as life events unfold. This concept begins with internal and/or external events, primary and secondary stressors (Pearlin et al., 1990). While existing models are only concerned with stressful events, the model of ongoing appraisal represents the elevation of joys to the same level as stressors, aligned with the modified model discussed above. As such, these events have the potential to be a stressor, a joy, or a combination of the two (Folkman, 1997), or neither (irrelevant). Similar to Lazarus and Folkman's (1984) model, appraisal processes are still at work, determining whether an event is appraised as taxing, joyous, or irrelevant, leading to secondary appraisal and the employment of coping strategies and resources. This model simply shows how experiences are happening as the social is unfolding.

Figure 2.5 - Ongoing appraisal – a close up



To sum up, current conceptualizations of stress processes have only provided limited insights into caregiving experiences, and have primarily focused on negative factors associated with caregiving. Only recently have researchers begun to explore the more positive sides of caregiving. In modifying and providing new conceptual insights described above, my hope is to explore and gain a better empirical understanding of caregivers' lived-experiences. A modified theoretical model was offered using the theoretical conceptualizations of Lazarus and Folkman (1984), Folkman (1997), and Pearlin et al. (1990). This model seeks to gain a better understanding of caregivers' lived-experiences by blending these two models and by focusing on the joys of caregiving. Lastly, to provide for a more dynamic understanding of caregivers' lived-experiences, the concept of ongoing appraisal was introduced, which attempts to conceptualize the dynamic nature of caregiving and how people ongoingly assess their situation. The purpose of offering this modified model is to gain insight into caregiving for individuals with chronic conditions by using a theoretical framework that does not occur within a vacuum of distress, outside of ongoing processes. As will be discussed in chapter III, this modified model is not intended to restrict inquiry, but to frame it and provide a theoretical lens that will gain insight into caregiving for children with ASD.

Families Living with ASD:

It was nearly 65 years ago that Leo Kanner (1943) reported findings from eleven case studies of persons who had "autistic disturbances of affective contact". Autism Spectrum Disorders (ASD) is a disability characterized by a triad of qualitative impairments. The core deficits are manifested in areas of 1) communication, 2) reciprocal interaction, and 3) restricted, repetitive behaviours and interests (Seltzer et al., 2004). Impairments in communication are manifested in both expressive and receptive language development, where some children may never develop meaningful communication skills (Seltzer et al., 2004: 236). For those who do have verbal communication, often those with high-functioning autism or Asperger's Syndrome, abnormalities in prosody and volume (ibid) in addition to limited topics of speech may occur. In the area of non-verbal communication, impairments include lack of eye contact (children with ASD might not look at you, but through you) and inappropriate body gesturing (Gray, 1998). The second

major qualitative impairment includes deficits in reciprocal and social interactions including inappropriate use of “nonverbal behaviors to regulate social interaction, difficulty making friends, limitations in shared enjoyment of interests with others, and a general lack of social or emotional reciprocity” (APA, 2000 cited in Seltzer et al., 2004: 237). The last core area of deficits includes restricted, repetitive behaviours and interests, primarily in three overlapping domains: behavioural (such as perseverations, aggressions, tantrums, head banging, and self-injurious behaviours), communicative (repetitive speech), and cognitive (obsessive tendencies and limited interests).

While these are all core deficits that constitute ASD, ASD is a spectrum disorder. Individuals who have the disability are heterogeneous; the severities of impairments for individuals who have ASD vary from person to person (for further discussion, see Duchan, 1998; Gray, 2003; and Seltzer et al., 2004). ASD is also often accompanied by mental retardation (Gray, 1994) and other co-occurring disorders (see Fombonne, 2003). Based on current population prevalence rates, it is estimated that around 1 in 166 (Center for Disease Control⁴) to 1 in 364 (Fombonne, 2003) individuals in the population have ASD. While this represents an increase in ASD over the past 30 years, it is unclear what has caused this increase (Fombonne, 2003; Gray, 1998). Reasons for the increase in prevalence of ASD may include greater awareness of the disability, broader definitions of ASD, and/or true increases in the disability. Differences in prevalence rates are most likely due to differences in methodologies used (for further discussion, see Fombonne, 2003). It is also important to note the political nature of prevalence rates, especially in the case of ASD. Nevertheless, it is suggested that around 50,000 children and 150,000 adults in Canada are impacted by an autism spectrum disorder, and the number is growing (Debates of the Senate, April 2007; The Standing Committee on Social Affairs, Science, and Technology, March 2007).

The line between mothering and caregiving is often blurred. Problems therefore arise in conceptualizing and trying to differentiate between these terms, as caregiving often overlaps with parenting. However, caregiving for individuals with disabilities can be characterized by its atypical nature, by the intensity, complexity, and duration of assistance involved, compared to parenting a child who is typically developing (in the

⁴ http://www.cdc.gov/ncbddd/autism/asd_common.htm, accessed December 2006.

context of this study, typically developing refers to non-ASD individuals). Also, the work of caregiving often requires parents to acquire specialized knowledge unique to their child's disability, meet with healthcare professionals at different stages of the child's development, and gain unique skills often associated with the work of healthcare professionals (Leiter et al., 2004). Lastly, caregiving roles are ever-changing as both the child and caregiver age and new challenges present themselves. As such, the caregiving role is not one that is often anticipated or one that can be fully prepared for (Pearlin et al., 2005). While the differences between parenting and caregiving can be distinguished from normative tasks of parenting and nonnormative tasks that make up the role of caregiving, for the purposes of this study, I do not distinguish between caregiving and parenting tasks, and use the terms interchangeably as the tasks involved in parenting and caregiving for children with chronic conditions often overlap.

Stressors and negative outcomes (stress)

The stressors and negative outcomes associated with caring for a child with ASD are well documented (Boyd, 2002; Burrell, Thompson & Sexton, 1994; Donovan, 1988; Dunn et al., 2001). Furthermore, because of the unique symptomatology associated with ASD and the difficulties associated with caregiving for a child on the autism spectrum, comparative studies have reported that the stressors and negative outcomes of caregiving for children with ASD to be greater than parenting a child with other disabilities, such as mental retardation, downs syndrome, cystic fibrosis, chronic and fatal physical illness (Dunn et. al, 2001; Hastings et al., 2005; Huws et. al., 2001; Pakenham et al., 2005; Sivberg, 2002; Weiss, 2002).

Marian DeMyer (1979) was one of the first to document the stressors and negative outcomes associated with mothers being the primary caregivers of children with ASD. During the early years of their child's development, she found that mothers often reported feelings of guilt, doubts of their ability to care for their child, anger towards the symptoms of ASD, increased physical and psychological tensions, frustrations, lack of life satisfaction, and feelings of exhaustion and old age. DeMyer explained that one source of this stress (stressor) was the autistic traits themselves; the child with ASD is

often unable to understand what is expected of him and often is not able or does not master the normative developmental tasks of childhood (1979: 149).

Sociologist David Gray (1998) interviewed 33 parents of children with ASD to explore the effects on families living with ASD. He reported mostly negative effects on families, including a combination of emotional problems (such as depression, isolation, feelings of being a failure as a parent), physical problems (fatigue, ulcers, headaches, fluctuation in weight, dermatitis, and other non-diagnosable physical health condition likely due to somatization caused by stress), career problems (limited or no employment specifically for mothers, career changes) and effects on the marriage (marital discord often ending in divorce, ASD as a source of disagreements between spouses). Similar to DeMyer, Gray found that the main sources of stress arose from the autistic traits themselves. However, Gray (1998) does note that for some parents, marriages were strengthened and spouses were brought closer together as a result of caregiving for a child with ASD.

More recent studies on caregiving for children with ASD are consistent with DeMyer and Gray. Rivers and Stoneman (2002) suggest that autistic traits, such as a lack of verbal communication, limited cognitive functioning, and severe behaviours (Dunn et al., 2001; Weiss, 2002) were most stressful for parents. Similarly, Tomanik et al. (2004) explored the relationship between maladaptive behaviours and adaptive behaviours of children with ASD, and maternal stress levels. Their findings suggest that what might be described as maladaptive autistic behaviours⁵ were most stressful for mothers. Their conclusion suggests that it is the traits that are associated with ASD that are the source of stress for most parents; whereby the autistic traits make it hard for the child with ASD to cope with their environment, this is further transferred to parents. The negative outcomes of such stressors included psychosocial burdens such as depression, anxiety, and anger (Gray, 2002a: 217), similar to those first reported by DeMyer.

The finding that the characteristics of the disability are the source of stress for caregivers is also supported in research of caregivers of individuals with dementia. Chappell and Penning (1996) suggest that it is the behaviours that result from dementia

⁵ When the child was “more irritable, lethargic/socially withdrawn, hyperactive/non-compliant, unable to take care of themselves, and unable to communicate or interact with other...” (Tomanik et al., 2005: 24).

that are most problematic for those who provide care (cited in Chappell et al., 2003). The psychosocial burdens for caregivers resulting from this stressor, for example, were “depression, guilt, worry, anxiety, loneliness, emotional stress and strain, lowered physical functioning, lower social functioning, worse general health” (Ibid, 366).

In addition to the child with ASD being a source of stress for families, Gray (2002a; b; 1998) explored stigma as a source of stress experienced by parents. Using the work of Goffman (1963), Gray suggests that this population of caregivers provides a fertile ground to explore both enacted (rejection and discrimination) and felt (feeling shameful or the fear of rejection) stigma. Gray uses Goffman’s concept of courtesy stigma – individuals who associate with stigmatized person(s) are also stigmatized through proxy. While past research has focused on individuals who have the option to associate with stigmatized groups (Gray, 2002b: 736), parents of children with ASD are in a contradictory position where they are stigmatized by their parental relationship to their child, and would most likely be condemned if they refused the association (Ibid).

Gray (2002b) found that a majority of parents of children with ASD experienced felt stigma. They sensed that others viewed their parenting ability to be poor, or experienced embarrassment due to their child’s behaviours when in public. Enacted stigma included social isolation from other families (i.e. not being invited over for dinner or parties), as well as hostile staring or rude comments. However, Gray (2002b: 740) points out that felt and enacted stigma often overlap and merge experientially. In his research on families of children with high functioning autism (HFA), Gray found that one outcome of social stigmas was the isolation of families and children, increasing the burdens of caregiving. Furthermore, because HFA is not as discernable as more severe forms of ASD, onlookers tend to react more negatively because they may not suspect a disability. Gray (2002a; b) also found a gender difference in the experience of courtesy stigma; mothers were more likely than fathers to experience both felt and enacted stigma. This difference is most likely due to mothers often being the primary caregiver and thus being in public with the child more often than fathers (Gray, 2002b: 743).

While both parents are affected by having a child with ASD, it is often the mother who becomes the primary caregiver because of the amount of time needed to care for the child and the differences in gender roles and earning power for men compared to women

in western societies (DeMyer, 1979; Gray, 2003). Due to their greater involvement in providing care, increased stigmatization by the community, and often no alternative role to that of caregiver, mothers are more likely than fathers to experience severe distress (DeMyer, 1979; Gray, 1998; Leiter et al, 2004). However, caregiving research primarily focuses on older caregivers who provide care to their aged parents or spouses. The caregivers of children who have extensive and unusual needs due to chronic conditions or other special needs conditions are less studied. In other words, young or middle-aged mothers who caregive for children with disabilities have been under-studied, but are of equal importance to the broader constellation of caregivers (Leiter et al., 2004).

Parents are not the only ones affected by caring for a child with ASD. Research on children who have a sibling(s) with a severe disability has shown that they have strong, playful relationships characterized by loyalty to their disabled sibling. Also, they are often aware of their sibling with ASD's activities and developmental gains (Wilson et al., 1988). However, due to the characteristics and impairments associated with ASD, such as the child being limited in how he plays and socially interacts with others, expresses a lack of emotion (such as fear, sadness, anger, and pleasure), and often has poor communication skills (Kaminsky and Dewy, 2001; Rivers and Stoneman, 2001), relationships are often characterized by less interaction between a sibling with ASD and a sibling without ASD (Stoneman, 2001: 135). Furthermore, Gray (1998) found that parents spend less time with and give less attention to their non-ASD children, which can result in the non-ASD child having feelings of resentment to both parents and sibling(s) with ASD.

Because of the stressors and negative outcomes for parents associated with caring for a child with ASD, the siblings of the child with ASD may be affected in a negative way. Hastings (2003: 101) reports that some siblings of children with ASD have more peer problems, adjustment problems, and lack prosocial behaviour (the tendency to voluntarily help others) when compared to children without a sibling with autism. However, some siblings of children with ASD cope better with the disability than others; they are accepting and can be a source of joy for parents (Gray, 1998). In other instances, sibling relationships have the potential to result in sibling conflict because of the social deficits associated with ASD (Know et al., 1995 cited in Kaminsky and Dewey, 2001).

While siblings of children with ASD are outside the scope of this study, sibling relationships have the potential to act as a major stressor on mothers and the rest of the family, especially when such relationships are rife with conflict (Stoneman, 2001).

The majority of research on caregiving for individuals with ASD focuses on autistic traits as the major stressors experienced by families and those who provide care. However, because of the nature of ASD, parents often need help in caring and providing support for their child with ASD. Formal supports (paid assistance) are numerous and might include behavioural management therapy and consultation, psychotherapy, art and music therapy, psychiatric therapy, speech and language therapy, occupational therapy, medical services, dental services, special care providers (M. Smith, 1990), etc. Parents' utilization of formal support services often begins before a diagnosis of ASD is given (during the diagnostic process) and continue throughout their child's development (Gray, 1998). Formal supports for individuals with ASD and their families, however, have been understudied. Furthermore, DeMyer (1979) and Gray (1998) suggest that formal supports have the potential to act as stressors for parents. These supports, however, might also act as joys.

For example, the process of diagnosing ASD can be a significant stressor for families, whether the outcome is a diagnosis of ASD or not (Howlin and Moore, 1997 cited in Whitaker, 2002). In accessing formal supports during the diagnostic process, DeMyer (1979) and Gray (1998) described how parents often felt unheard by medical practitioners when they expressed concerns about their child. Gray (1998: 146) wrote:

Many parents reported that doctors they consulted at this time (during the referral process of the diagnostic process) denied that their child had a medical problem. Instead, parents were sometimes advised that they were exaggerating the matter or that they were responsible for the child's behavior. As a consequence, they were often extremely distressed by self-doubts about their parental abilities.

Supporting these findings, in an earlier unpublished study entitled "The Diagnosis Process of Autism: from a mothers standpoint", Corman (2005a) employed Dorothy Smith's institutional ethnography to describe the lived-experience of a mother during the diagnostic process associated with autism. This study described the fight of a mother as she was co-opted into relations of ruling to participate in a discursively mediated world of a clinical pathway where a diagnosis (label) was needed in order to obtain adequate

support for her child. By showing the bifurcated consciousness of a mother (Smith, 1987) as she moved between the world of parenting, caring and worrying about her child, and the world embedded within the medical model of health, where she must make her child fit into categories deemed suitable for diagnosis, the work of a mother was depicted during the diagnostic process of ASD (Mansell & Morris, 2004). This study also illustrated some of the stressors and negative outcomes associated with services and supports that are meant to be helpful for parents, such as the mother feeling as if she was not being heard and feeling hurt by the health professionals she came into contact with. On a similar note, DeMyer (1979) found that 57% of parents had nothing positive to say about their experience with the experts.

DeMyer (1979) and others suggest that parenting a child with ASD involves multiple stressors that vary depending on the family and the severity of the child's condition. These multiple stressors can have an immense effect on individuals in the family, including parents and their relationship with each other, non-ASD siblings (DeMyer, 1979; Schopler and Mesibov, 1994), and other family members (Gray, 1998). ASD not only impacts the child who has the disability, it is a chronic condition that potentially acts as a stressor on the entire family and those who care for the child. It is important, then, for families to develop coping strategies and resources in order to deal with a variety of stressors and negative outcomes. Therefore, there is a great need to explore the stressors and parental-coping associated with parents of children with ASD (DeMyer, 1979) in order to gain a better understanding of their experiences and facilitate better services, supports, and caregiver and care receiver outcomes.

Coping and Social Support

Even before the initial diagnosis of ASD, parents must develop and employ coping strategies and resources to buffer stressors. This continues throughout every aspect of their child's early development (DeMyer, 1979), and as the child with ASD ages into adulthood (Gray, 2006). Pearlin and Schooler (1978: 3) define the concept of coping as "any response to external life strains that serves to prevent, avoid, or control emotional distress". Lazarus and Folkman (1984) describe coping as a shifting process that varies depending on the stressful encounter or experience, allowing for individuals to

mediate the effects of stress on their well-being (Kelso et al., 2005) by managing both internal and external demands (stressors) that are appraised as stressful (Folkman and Moskowitz, 2004; Lazarus and Folkman, 1984 cited in Kelso et al., 2005: 3). As previously mentioned, coping can consist of five different resources: social support networks, utilitarian resources, general and specific beliefs, problem-solving skills, an individual's health, energy, and morale, and two types of strategies: emotion-focused and problem-focused coping (Kelso et al., 2005; Folkman, 1997; Opperman & Alant, 2003). Coping, then, refers to efforts, either conscious and/or behavioural, that mediate the effects of events that are appraised as taxing and thus stressful (Weiss, 2002), and represents a major factor that determines a person's health and well-being (Matheny et al., 1986). Effective coping, therefore, can minimize the stressors and negative outcomes associated with caring for a child with ASD (Sivberg, 2002). For the purposes of this study, parental coping refers to the use of strategies and resources, including social supports, both formal and informal (Gray, 1994: 287).

Gray (1994) studied parental coping for families of children with Asperger's Syndrome and suggested that coping strategies and resources included, but were not limited to, the use of formal support (treatment services), informal support (family and friend support), religion, social withdrawal, and individualism, (including employment, recreation and political activities) (Gray, 1994). In a later study of families of children with more severe forms of ASD, Gray (1998) found that the most successful strategies included social supports. In order to cope with social stigmas, parents often avoided social interactions, ignored the stigmatizing behaviours, tried to explain their child's disability to onlookers, or used humor to cope with stigmatizing behaviours of the general public (Gray, 2002b).

Positive coping strategies for Dunn et al. (2001) consisted of both emotion-focused strategies, including positive reappraisal, and problem-focused strategies (confrontive coping) and seeking social support. These types of coping styles corresponded to positive outcomes.⁶ However, some emotion-focused styles of coping,

⁶ "Positive reappraisal includes such things as growing as a person, finding new faith, rediscovering the important things in life, and being inspired to be creative. Confrontive coping includes fighting for what is wanted, expressing anger to the cause of the problem, letting feelings out somehow, and taking chances" (Dunn et al., 2001: 50).

such as escape-avoidance and distancing, were associated with negative coping styles and sometimes led to stressor outcomes (Dunn et al., 2001: 49). Research has also found that people tend to cope using a mix of both strategies (Lazarus, 1996, cited in Gray, 2003: 632; Gray, 1998) depending on the context of the stressful event. This understanding of coping is consistent with the conceptual framework offered by Lazarus and Folkman (1984) and Pearlin et al., (1990).

As mentioned above, caregiving usually falls on the shoulders of women, who are often unpaid and unrecognized (Chappell and Penning, 2004: 11; Chappell and Reid, 2002: 5). With a larger responsibility of care, the effects on mothers caring for their child with ASD are often more direct and more severe than the effects on fathers (DeMyer, 1979: 150). There is a need to recognize that people's stress processes, coping strategies, and resources are embedded in the contexts of their lived-experiences. As such, Gray (2003: 642) emphasizes the importance of recognizing people's experiences in a broader social context where a multitude of socio-economic and ideological factors are relevant. For example, Gray (2003: 635) suggests that fathers are not impacted as severely as their partners due to the way gender roles impact the decisions about who goes to work and who stays home to care for the children. The very activity of going to work, for instance, can be considered a way fathers cope because it can alleviate the stressors associated with having a child with ASD; work can essentially be thought of as a form of respite care for the father. Mothers, on the other hand, are often restricted to the traditional gender role of primary caregiver. This restriction is one possible cause of the severity of stress mothers often experience and their need to develop strategies and resources to cope that differ from what fathers develop (Gray, 2003: 642).

The social support system also can mediate the impact of stressors and is therefore a parental coping resource (Trute and Hiebert-Murphy, 2002). Chappell and colleagues (2003) provide an overview of social support and the way it is and has been applied in research. They suggest that social support is a broad term that means different things to different people; sometimes connoting positive interactions and other times connoting neutral or negative interactions. They go on to describe how early research conceptualized social support by its affective and emotional aspects (see Cobb, 1976; cited in Cohen and Syme, 1985; Lopata, 1975;) while others such as Pearlin (1985) and

House and Kahn (1985) differentiated among social network, group affiliation, and interpersonal interaction and social networks, social support and social integration respectively (cited in Chappell et al., 2003: 345). Social support can further be divided into formal and informal support. Formal support can be defined as paid assistance given to an individual or group of individuals by a group or agency. Informal support can be defined as unpaid networks of people, including family, friends and neighbors, who provide some type of support that encompasses both functional (assistance with activities of daily living) and structural (the existence of social relationships) characteristics (Huws et. al., 2001: 570).

The importance of having at least one source of social support to counter the stressors and negative outcomes related to caregiving for a person with a chronic disability is paramount (Dunn et al., 2001; Pearlin, 1981; Pruchio, 2003). The benefit of social support for reducing the impacts of stressors and negative outcomes is well documented. In her discussion of formal and informal elements of social support, Weiss (2002) highlights the importance of informal support from partners and relatives as comprising a powerful buffering effect on reducing negative outcomes. Boyd (2002) found similar results for caregivers of children with ASD, suggesting that informal sources of social support, specifically spousal support, were the most effective for buffering against negative outcomes. Pruchio (2003: 851) further supports this claim by suggesting social support from friends and family decreases the stressors and negative outcomes associated with caregiving.

The use of formal sources of support is also paramount when caring for a child with ASD. Boyd (2002) mentions the benefit of parent support groups where parents of children with ASD come together and discuss issues surrounding their child; this source of support was found to act as an effective buffer to negative outcomes. Furthermore, there is a positive relationship between parental satisfaction with social support networks and their overall relationship with their child with ASD (Dunst et. al., 1986; Raif and Rimmerman, 1993).

Respite care is a formal service used by parents of children with disabilities that allows families to leave their child with a professional caregiver for a certain amount of time. Respite is defined as a break or “pause in or temporary cessation of caregiving tasks

and an interval of rest” (Chappell et al., 2003: 368). This type of service is intended to provide a break for caregivers, allowing them to recoup and reenergize. Such services are unique in that they target the needs of the caregivers rather than the recipient of care. Respite care has been shown to decrease the impact and severity of stressors and negative outcomes in families of children with ASD. Also, the perceived availability of respite care is essential in assisting families in continuing to provide care for their child with a disability at home and avoid out-of-home placement (Abelson, 1999). Abelson also examined the cost effectiveness of providing respite care in comparison to institutionalization or residential homes; he suggests the cost of respite care in the short-term is less than the cost of institutionalization in the long term (Abelson 1999). These findings are supported by Chappell et al., (2004) who researched other domains of caregiving. They found that providing home care for seniors to facilitate them living in the community was less costly than providing long-term residential care.

However, Chappell et al. (2003) suggest that the benefits of respite for caregivers have been inconsistent at best. In trying to understand this inconsistency, Chappell and colleagues note that current conceptualizations of respite, from both researchers and service providers, have gone astray. Rather than viewing respite as an outcome (break), they have conceptualized it as a service; caregivers should first be asked to identify what a break means to them to assess the impact of the service (Chappell et al., 2003: 369). To situate respite within the conceptual lens of this research, a break must be appraised by caregivers and not measured as simply a service provided. This conceptualization of respite can be broadened to include both formal and informal sources of support, where it is not the objective supports given to parents but how parents appraise the supports that is important for their well-being. A study by White and Hastings (2004) specifically illustrates this conceptualization of informal support. They found that parents of children with severe developmental disabilities who appraised informal supports as supportive and helpful reported higher levels of well-being compared to those who did not appraise the support as helpful. They went on to describe how the perception of this support, or how it was appraised, was the most significant factor related to parental well-being.

Due to the ambiguity surrounding the term social support, Chappell et al. (2003) emphasize the importance of defining what one means by this term, because it cannot be

assumed. Furthermore, the majority of research has provided a singular view of social support as inherently positive (in the sense of mediating stress), failing to account for other aspects of social support, such as the neutral or negative aspects. This is also true with research on ASD. For these reasons, social support (either informal support, which refers to unpaid assistance from family and friends, or formal paid support) is used here to refer to social interactions that have a potential impact on caregivers in a positive, negative, neutral, or a mixed, way. In this definition, I attempt to incorporate the multidimensionality of social support by accounting for the varying types of impacts on the receiver of the support (White and Hastings, 2004). In line with the transactional model of stress, it is conceptualized that social supports impact individuals depending on how it is viewed by support receivers, not the intended purpose of the support. Furthermore, I explore both sides, the positive and the negative aspects, of social supports and their impact on caregivers.

Joys of Caregiving

While the majority of this chapter has examined the negative/stressful side of caregiving, and despite the need to study the stressors, negative outcomes and parental coping associated with parenting children with ASD, there is still an aspect of parents' lived-experiences that is unaccounted for, the *joys of caregiving*. Grant et al (1998), similar to Folkman (1997), found that caregivers experienced joy derived from providing care. Grant et al. (1998: 62-63) outlined gratification in caregiving as arising from three different sources:

Rewards emerging from the interpersonal dynamic between caregiver and relative; those deriving primarily from the intrapersonal orientation of the caregiver; and finally, those stemming from a desire to promote a positive or avoid a negative outcome for the person with the intellectual disability⁷.

Each source is related to a beneficiary: the person with the disability, mutual benefit between caregiver and person receiving care, and the caregiver, independent of the person receiving care. Grant et al. (1998) also found that many of the gratifications

⁷ Intrapersonal qualities include "strengthened faith, tolerance, personal growth, skill development and career expansion" (i.e., rewards arising out of the caregivers desire for positive or to avoid negative outcomes). Interpersonal qualities include "strengthened family ties and expanded social networks" (Grant et al., 1998: 59).

expressed by caregivers in his study were related to, or were a product of, event outcomes or successful coping strategies occurring within the stress-coping process.

In a study of 167 primary caregivers that compared caregiving for children with a mental disability to those with a physical disability, Chaya Schwartz (2003: 578) explored two aspects of the caregiving experience: caregiver gratification (how caregiver's experience was emotionally and psychologically rewarding), and factors that led to caregiver gratification. She found that both the child and caregiver's characteristics and the burden experienced by caregivers contributed to caregiver gratification, which she defined as "fulfilling parental duties, a better idea of 'what's important in life', learning about inner strengths, awareness of personal limitations, learning to do new things, satisfaction from doing what's right, personal growth, and becoming more self-confident" (Schwartz, 2003: 580). More specifically, the personal characteristics that predicted gratification included caregiver's age, employment status, and health: those who were younger, unemployed, and who had poor health were more likely to experience caregiver gratification. In addition, she found the only characteristics of the child that factored into experiencing gratification for caregivers was the age of the child (younger children) and the type of disability (having a physical rather than a mental disability). Subjective (perceived stress) rather than objective burden (the level of care required), was associated with less caregiver gratification (Schwartz, 2003: 582). As Schwartz explains, the psychological and emotional gratification that parents experienced might be a product of how they perceive or how they create meaning in their caregiving role. In a study conducted in British Columbia, Chappell and Litkenhaus (1995) found that caregivers listed a range of rewards from caregiving, including seeing the care receiver happy, personal growth of the care receiver, and the closeness of the relationship (cited in Chappell, 2003: 367).

Research with a focus on the positive factors associated with caregiving for a child with ASD is in its beginning stages. For instance, Amos Fleischmann (2004) conducted a study that focuses on the positive aspects of caregiving for children with ASD. In her study of narratives published on the Internet, Fleischmann found that a majority of parental websites focused on the positive essence of their child's disability, with an emphasis on the joyful aspect of caregiving in addition to the more difficult

aspects of caregiving for a child with ASD. Her study is supported by other research that focuses on contributions that people with disabilities make to their families; families might benefit in the sense of strengthened family ties, compassion and fulfillment, and happiness (Pruchno, 2003: 851).

Corman's (2005b) study, "The Stresses and Joys of Parenting", explored the lived-experiences of three parents. The sample was purposively chosen so that one parent had typically developing children, one had a child with attention deficit disorder, and one had a child with Asperger's Syndrome, which is on the autism spectrum. In addition to talking about the stressors of caregiving, parents were asked to describe their joyous experiences of parenting during the early years of their child's development (between the ages of one and five years old) and as their child aged into early adolescence. Parents described the joy of spending time together with their children, such as going to the beach with their children and going for walks. Parents also expressed joy derived from, as one mother described it, "just watching kids being kids". For instance, the father described watching his youngest child during the Twins' baseball games where "she would play with other kids; twiddling around on those scooter things...that's lots of fun". Parents also described the happiness of watching their child grow and develop. The father discussed the "joy and entertainment" derived from his daughter's "spectacular language development...she was so precocious and cute...her intellectual success is quite enjoyable". This fun and success brought "joy into [the father's] life". One mother described the joy of watching her son finally going to school "and enjoying himself there, making friends". The mother of a child with Asperger's Syndrome also expressed the joy of watching her child's personality "come out". Lastly, parents expressed the joy of just being a parent.

In the same study, all parents derived joy from their child experiencing joy, often occurring at the same time as other joyous experiences. However, the mother of a child with Asperger's Syndrome derived joy from watching her child grow and develop the ability to communicate, which in turn provided hope for her child's future. Whereas the mother with typically developing children and the father with a child with attention deficit disorder described joy derived from their child's "normal" development, the joy derived from parenting a child with Asperger's Syndrome arose out of not knowing

whether her child would be able to communicate or how far he would develop. To watch her child develop was very joyous.

In addition to exploring the stressors and joys of parenting, Corman's (2005b) findings also supported Folkman's (1997) findings that stressors and joys can co-occur. Two parents reported a particular event that was both stressful and joyous. Both parents described their experience of divorce. They described parenting during this event as being both joyous and stressful. The father described divorce for his kids as consisting of mixed events where they "misbehaved all the time, in certain ways, but in other ways they responded really well". He went on to describe the "love/hate" relationship with "the new mother", and how eventually "they began to thrive slowly and surely". The mother of a child with Asperger's Syndrome described her divorce as a relief for her but for her child, "it was very difficult, he was going downhill big time". Despite the difficulty in seeing her child suffer during the initial separation process, she described the divorce as "the best move for him". Both parents reported difficulty in the initial process of the divorce, but as being the best move for their child in the long-term.

Studying the joys and more positive aspects of caregiving for children with disabilities is a relatively new domain for researchers. While this represents an important shift in research, a major limitation still evident is that we do not yet know the role of joys within caregiver's stress-coping process and their overall impact on caregivers. By systematically exploring the joys and stressors of caregivers of children with ASD, more will be learned about the experiences of these parents. This has the potential to provide for a better understanding of the nature of the stressors, joys and parental coping, and contribute knowledge to parents of children with ASD and caregivers of individuals with other chronic conditions.

Out-of-Home Placement

Since the early 1970s, there has been a movement towards deinstitutionalization of individuals with disabilities to community-based settings. As a result, parents are providing care over longer periods, often as perpetual parents (Botsford and Rule, 2004). Today, society normalizes families living together. Social forces encourage families to provide care for family members living with a disability (Cummins, 2001). However, not

all families who have children with ASD and other disabilities are able to do this. Gray (2002a) found that most families developed coping strategies that resulted in favorable outcomes with their experience of caring for a child with ASD. However, roughly 25 percent of children with ASD are described by their families as being aggressive and/or severely obsessive (Gray, 2002a). Families whose children with ASD exhibit severe behaviours experience more negative outcomes and severe stress. This often worsens as their child ages and becomes less controllable (Gray, 2002a). Furthermore, these families have a multitude of needs that require different types of services and support (Kohler, 1999), without which families might not be able to care for their child (Blatt et al., 1977; Cole, 1986). Due to the severity of ASD in some cases, and possibly other unknown factors, not all families are able to cope. Such a situation can lead to placement where the child is enrolled in a residential treatment-care facility, a foster-care home, and/or a group home (Gray, 2002a; Sherman, 1988).

One of the most stressful experiences for parents of a child with a disability is the decision to place. Freedman et al. (1997: 114) note that the decision to place is a time that is often accompanied by turmoil between family members and fluctuations in personal and familial well-being. Smith, Tobin and Fullmer (1995: 487) describe it as one of the most difficult decisions because parents must acknowledge the prospect of their child not remaining in their life-long home. The literature that deals with placement of individuals with disabilities tends to focus on older populations than the sample of this study. Furthermore, there is not a specific focus on ASD. Despite the limitations of current research, an examination of the aspects involved in placement of individuals with disabilities offers a launching point to situate the placement of individuals with ASD.

A parent's decision to place is very complex, consisting of a multitude of factors (Bromley and Blacher, 1994; Freedman et al, 1997; Smith et al., 1995). Such factors include the individual characteristics of the person with a disability (severity of the disability and behaviour problems) (Bromley and Blacher, 1994; Freedman et al., 1997), family characteristics (Cole, 1986), and outside influences that act as stressors on the family (employment, death, and other stressful life events that can impact families and their ability to provide care for their child with a disability). (For further discussion, see Thorsheim and Bruininks, 1978).

Tausig (1985) found similar factors leading to placement. His findings suggest that predictors of placement differ according to the age of individuals with developmental disabilities⁸. For instance, for parents whose child with a disability was 21 years of age and younger, Tausig found that individual characteristics, including the severity of behaviour problems, the age of the child (older), the sex (male), and the number of diagnoses of the child were all predictors of placement. He also found that family characteristics, such as the number of young children in the household and family mental health problems were predictors of placement. However, he concluded that the child's behavioural problems were more important than other factors associated with placement (Tausig, 1985: 358). For parents of children 21 years of age and older, the child's functioning level was a more significant factor leading to placement than behaviour problems. Family characteristics, such as other family members' problems, played a minor role in placement. Stressors within the family, such as burden of care and disruption of family relations were the most significant indicators for placement. This led Tausig to conclude that for this age group, the impact of the disabled adult on the family should be seen as integral to a parent's decision-making process (ibid).

Sherman (1988) expands upon the understanding of parents' decision to place their children with disabilities by examining environmental factors that impact the family's ability to care for their child with a disability. Sherman (1988: 345) explored three related factors linked to a parent's decision to place their child with a developmental disability: family characteristics, coping resources, and social support. Sherman developed a set of risk factors for families likely to place their child in out-of-home care. These included: the greater the age of the child with the developmental disability, the more severe the behaviours and disability, the larger the family size, the greater the parents' age, the greater the marital discord (McCallion and Toseland, 1993), and the greater the appraisal of the situation as burdensome on the family (Sherman, 1988). In contrast, parents who had greater sources of both formal and informal support were less likely to place their child. He also found that children diagnosed as autistic were more likely to be in out-of-home placement (Sherman, 1988: 347), further supporting the need to study families of placed children with ASD.

⁸ He does not, however, differentiate between disabilities.

Tabatabainia (2003: 245), in a study that examined family views on institutionalizing and deinstitutionalizing their children with intellectual disabilities, explored parents' reasons for institutionalizing their child. Parents gave three primary reasons for placing their children: negative impacts on immediate family members' own lives, negative impacts on relatives, and negative impacts of care receiver on the community. An additional explanation presented by parents was that it reflected suggestions and encouragement from professionals to do so (Tabatabainia, 2003). Taylor (2005) also supports this finding.

Social exchange theory might also shed light on parents' decision to place. Social exchange theory suggests that relationships are maintained when perceived benefits outweigh the costs of maintaining the relationship (Blau, 1964 cited in Leming and Dickinson, 2002). Comparing kin and nonkin foster parents, Timmer et al (2004) used social exchange theory to explore how parents perceive their foster child. They found that nonkin caregivers perceived their foster child's behaviour problems as more severe and showed greater emotional distress compared to kin caregivers. These findings suggest that kin foster parents might have more emotional investment in their foster children (Timmer et al., 2004). Within the context of parenting children with disabilities, social exchange theory would suggest that parents would decide to place their child in out-of-home care when the perceived burden of care is greater than the benefits of keeping the individual with a disability at home (Tausig, 1985).

By focusing on placed children with ASD, this study enters into uncharted territory of caregiving for young children with developmental disabilities, the processes by which placement becomes necessary, and the stressors, joys, and parental coping associated with this time period.

Definition of Terms:

Because of the ambiguity surrounding terms within caregiving research, specifically stress research, and for purposes of clarity, I define key terms as they are used in this study in Table 2.1 below:

Table 2.1 – Definition of terms⁹

Terms:	Definition:
Stressor:	Stressors refer to events/experiences that have the potential to cause negative stressor-outcomes (stress), or co-occurring positive/negative outcomes depending on how the event/experience is appraised. Stressors have been grouped into two main themes: those that directly relate to caring for children with ASD. Pearlin et al. (1990) describe these stressors as primary stressors. And those external to the direct caregiving role but impact caregivers (Pearlin et al. (1990) describe these as secondary stressors). These direct and indirect stressors are not always clear-cut. Therefore, some confusion is inherent in this bifurcation. The purpose of separating the stressors into these porous categories is to provide a view of caregiving that takes into consideration forces outside of the direct caregiving role.
Joys	The joys of caregiving refer to the more positive and joyous side of caregiving. In this study, joys are used in a similar way as stressors – stressors suggest the potential to lead to stresses or negative stressor outcomes, and joys (which might be thought of as joy(ors)) suggest the potential for positive or joyous outcomes, depending on the context of mothers' lived-experiences.
Outcomes: Negative stressor-outcomes Co-occurring outcomes	<p>Outcomes are separated into negative stressor-outcomes, co-occurring outcomes, and positive/joyous outcomes.</p> <p>Negative stressor-outcomes or negative outcomes derive from an event (stressor) that is appraised negatively or taxing for individuals and result in solely negative outcomes. Borrowed from the gerontology literature, I define negative stressor-outcomes (stress or stresses) as either psychosocial burdens or behavioural outcomes, that are outcomes experienced by caregivers; “as the physical, psychological or emotional, social, and financial problems that can be experienced by family members” (George and Gwyth, 1986 cited in Chappell et al., 2003: 365). Within current conceptualizations of the stress-coping process, negative stressor-outcomes are directly related to caregiver outcome whether it be the well-being of the mother or her physical health (Chappell et al., 2003: 366).</p> <p>While stressors have the potential to lead to negative stressor-outcomes, this need not be solely the case. This is exemplified in the recent developments of the stress-coping process as they relate to the co-occurrence of stressors and joys (Folkman, 1997). Also, something positive can come out of something negative. This might be depicted in caregiver overall well-being.</p>

⁹ Singleton and Straits (1999: 100) explain, “the process of formulating and clarifying concepts, called conceptualization, is linked to theory testing and construction. This ongoing process may occur prior to any particular empirical investigation and it usually continues through research, as theories and their constituent concepts are refined and elaborated”. This explanation of theory-use is aligned with quantitative studies. However, this study is qualitative in nature so this definition of theory-use is not the case. As Creswell (2003: 131-132) discusses, theory-use in qualitative studies can be used in several ways: as an “explanation of behavior and attitudes” (similar to quantitative studies), as a theoretical lens or perspective that guides the study and raises questions that the researcher wishes to address, or as an inductive logic of research and theory where the development of theory becomes the study’s “end point”. This study uses aspects of all three theory-uses.

Positive/Joyous outcomes	The positive/joyous outcomes refer to those that derive from the joys of caregiving, either directly from the caregiving role or external to it. Furthermore, co-occurring outcomes are also part of the joys of caregiving. Similar to stressor outcomes, joyous outcomes refer to psychosocial and behavioural outcomes. The joys and positives of caregiving remain a relatively uncharted territory, lacking conceptualization and measurement (Grant et al., 1988: 59).
Parental Coping:	For the purposes of this study, I use the term parental coping to describe the use of strategies and resources (emotion-focused coping, problem-focused coping, and a mixture of the two), and social supports that mediate the impact of stressors and outcomes. Social support refers to either informal support (which refers to unpaid assistance from family and friends) or formal, paid support that results in interactions between individuals that are either positive, negative, neutral, or a combination of either, and impact caregivers in an either positive, negative, neutral, or combination, way.
Ongoing appraisal:	This term conceptualizes how past events/experiences have an impact on present and future appraisal processes. This term attempts to add to the stress-coping models discussed by Lazarus and Folkman (1984) and Pearlin et al. (1990) by providing for a more ongoing and dynamic examination of people's lived-experiences.
Placement:	The term placed children with ASD or placement is used to refer to parents who, due to a multitude of conditions, place their child in out-of-home care either in foster-care or residential treatment-care facilities, what might be referred to as the "new institutions" (see Taylor, 2005).

Chapter III

Research Design and Implementation

The preceding chapters introduced and explained the background, problem statement, and purpose of this study. They also introduced readers to the conceptual framework that guides this inquiry, summarized research on caregiving for individuals with ASD (including the stressors, joys and how parents cope), and reviewed research on placement of individuals with chronic conditions. I have argued a need to explore mothers of placed individuals with ASD, as this is an understudied, and perhaps increasing population of caregivers. I also argued that there is a need to examine the joys in addition to the stressors of caregiving. This chapter outlines how I conducted this research. Following a brief introduction on qualitative research, I discuss the paradigm, methodological approach, method and recruitment of individuals, data analysis, strategies for rigor that were employed, and the pilot study conducted in preparation for this study.

Qualitative research is a heterogeneous field that is ever evolving and unfolding, with a long and illustrious history in the sciences (see Denzin and Lincoln, 1994). The nature of qualitative research is to gain a better understanding of the meanings of social events from the perspectives and experiences of those who are involved in them (Esterberg 2002). Fundamental to the rubric of qualitative research strategies and, more specifically, exploratory research, is the intent to identify, describe, and explain the social issue(s) at hand (for further discussion, see Miller and Crabtree, 1992). The mode of understanding in qualitative research differs significantly from quantitative research and involves alternative conceptions of social knowledge. The purpose of using qualitative data is based on the interpretation of meaningful interactions (Esterberg 2002; Kvale, 1996; Nieswiadomy, 1993). In other words, people are studied in their natural environments in an attempt to understand and interpret phenomena based on the meanings and context that people bring to them.

Paradigm:

In Chapter II, I introduced the reader to the stress-coping process purported by Lazarus and Folkman (1984) and Folkman (1997), and the stress-process by Pearlin et al. (1990) that theoretically frame this inquiry. By combining these two theoretical models

into a modified stress-coping process model, I attempted to provide for what Best calls a multiperspectival vision. He writes, where “no single theory or method of interpretation by itself can grasp the plurality of discourses, institutions, and modes of power that constitute modern society” (Best, 1995: 93). In addition, and based on the critique provided, I elevated joys to the same level as stressors within this modified model and conceptualized a more dynamic caregiving experience by introducing the concept of ongoing appraisal. It is important now to situate the theoretical framework into the paradigm that guides this inquiry.

A theoretical road map, worldview, or paradigm can be defined as the understanding with which a researcher approaches the study that guides the thinking and research (Macionis et al., 2005: 12). Paradigms usually consist of three components: a theory of reality (ontology), how we know what we know (epistemology), and a way of going about gaining insight into the world (methodology) (Chappell et al., 2007). Qualitative research is not limited to one specific paradigm and is often multiparadigmatic in focus (Denzin and Lincoln, 2005: 7). Furthermore, paradigms are not as distinct as they were once thought to be. Denzin and Lincoln (2005: 183-184) explain, “...the borders and boundary lines between these paradigms and perspective have begun to blur...the ‘pedigrees’ of various paradigms are themselves beginning to ‘interbreed’”.

The paradigm that best guides this inquiry falls under the rubric of interpretive-constructivist approaches characteristic of qualitative methods. This paradigm suggests that knowledge is socially constructed. This approach assumes a relativist ontology, a subjectivist epistemology, and a naturalistic methodology (Denzin and Lincoln, 1994: 13-14). Creswell (2003: 9) outlines three key assumptions of this paradigm based on what Crotty (1998) identified (see also Denzin and Lincoln, 2005):

1. Human beings construct meanings as they engage with the world in which they seek to interpret. Within this paradigm, the qualitative researcher often uses open-ended questions (discussed below) to allow participants to express their views.
2. Humans’ engagement with and interpretation of the world is historically and socially situated because we are social beings born into a world where meaning is bestowed upon us by our culture and personal backgrounds. The qualitative researcher seeks to understand the context and nature of the setting of participants through different methods of gathering information. It is recognized that

interpretation of participants' experiences are formed by the researcher's personal background and experience.

3. Meaning is generated inductively, through social interactions. The researchers' findings and interpretations are based on the data collected during the research process, not a product of a predetermined conceptual frame.

This paradigm seeks to gain a better understanding of the phenomenon under study; it relies mainly on participants' views of the situation being studied and draws attention to its complexity (Creswell, 2003: 8). In the context of this study, a more complete understanding of caregivers' lived-experiences is sought. Aligned with qualitative research, this paradigm uses an inductive approach to generating knowledge by beginning with interviews and moving towards identifying patterns based on the experiences of participants (Rudestam and Newton, 2001: 37). The purpose is not to impose assumptions or a systemizing structure prior to speaking with participants (ibid).

In stating knowledge claims, my purpose is to identify what assumptions were brought into this study and guided it throughout. It is important to note that the theoretical framework discussed in Chapter II, and the models illustrated, that theoretically frame this inquiry did not function as ideological practices. Dorothy Smith describes ideological practices as "methods of creating accounts of the world that treat it selectively in terms of a predetermined conceptual framework" (Rankin and Campbell, 2006: 135). This study is first and foremost an exploratory study with the purpose of exploring parents' lived-experiences. Theoretical models and the inclusion of joys were discussed in Chapter II and a model was developed to assist the researcher in framing this inquiry; I was not attempting to presuppose a theoretical assumption about parents' lived-experiences or the influence of joys directly related to or external of the stress-coping process.

In addition, the purpose is not to test the modified model discussed, which would be aligned with a deductive approach to data analysis (Babbie, 1992); conversely, the data collected inductively informs the model by seeking to gain a more complete understanding of caregivers' lived-experiences. For example, as the interviews with participants unfolded, the model was continuously modified to incorporate what was learned from mothers (discussed in Chapter V). This inductive approach aligns with the paradigm that the researcher brought into the study. This paradigm is also consistent with the philosophical assumptions integral to the methodological approach of

phenomenology that is used (Chappell et al., 2007; Creswell, 2003). This approach is explained below.

Methodological Approach:

In deciding what methodological approach to use in this or any other investigation¹⁰, many factors must be taken into consideration (Miller and Crabtree, 1992). As such, many approaches were considered prior to the decision to use qualitative methods, specifically phenomenology, to guide this inquiry. For instance, in exploring survey methods, Earl Babbie (1990) suggests that surveys provide the description, explanation, and exploration of an intended area of study. Whichever purpose surveys are geared towards, they are ultimately used to explore and explain the relationships between multiple variables (Moser and Kalton, 1971). A survey questionnaire was originally considered to compare the stressors and coping strategies and resources of parents of placed children with ASD to parents whose child with ASD lived at home. In order to do so, a non-probability purposive sample was originally proposed that controlled for age and functioning level of the child with ASD. While the intent of this type of research design would be to describe, explain, and compare and contrast the coping strategies and resources of these different populations of caregivers, this type of design was deemed not suitable for this particular investigation because of its exploratory intent.

Other qualitative methods were also explored and considered. One approach was a grounded theory design. This would have been appropriate if I were interested in developing a theory out of my data (Creswell, 2002), however this is not the intent of this study. Also, a narrative research design would have been beneficial if I were interested in telling life-stories about participants as it relates to their experience of caregiving (Creswell, 2002). While both qualitative and quantitative approaches would provide valuable information to the topic of caregiving for children with ASD, because I was more interested in exploring specific aspects of parents' lived-experiences as they relate to parental coping, stressors, joys and out-of-home placement, I chose a phenomenological approach to guide this inquiry. As Moerer-Urdahl and Creswell (2004) explain, this approach is valuable when a phenomenon is identified that needs further

¹⁰ In deciding a methodological approach to scientific inquiry, I acknowledge the debate surrounding the use of theoretical and methodological frameworks (Rodman, 1980; Smith, 2005; 1987).

investigation and has individuals who are available to provide descriptions and insights into the phenomenon. Utilizing qualitative, semistructured interviews with open-ended questions based on the methodological approach of transcendental phenomenology, can assist in gaining a better understanding of the nature of the stressors, joys, and parental coping for this population of caregivers.

It is important to note that the design of this study is not restricted, nor should it be, solely to the phenomenological approach. In fact, as Sandelowski (2000: 337) explains, any qualitative approach to social enquiry can have the “look, sound, or feel of other approaches” (also see Charmaz, 1990: 1164). Others suggest that “qualitative research is inherently multi-method in focus” (Denzin and Lincoln, 2005: 5). As such, this phenomenological study takes on a particular cast of grounded theory, specifically when the process by which placement occurs is explored. As placement of children with ASD is a relatively uncharted territory, the data from this study garnered from this time period potentially contributes to a theory on the processes by which placement becomes necessary. This is discussed in the concluding chapter. Furthermore, Dorothy Smith’s institutional ethnography, specifically her shift in epistemological and ontological ways of thinking that focuses on the way individuals are coordinated by forces outside of their local setting, what she calls translocal or extra-local relations of rulings that are textually mediated, is useful (See Smith 2005; 1999; 1990; and 1987). Casts of Smith’s underpinnings (as explained in Chapter II) were also useful in developing the concept of ongoing appraisal and assisted in exploring external forces that impact parents’ lived-experiences¹¹.

Steven Best (1995) calls for the need for critical theory to improve upon and expand towards a multiperspectival vision that brings modern and postmodern lines of

¹¹ IE is a sociology and methodological approach to social inquiry that explores how people are organized and coordinated by extra-local, textually mediated relations of ruling. The focus of an institutional ethnographic inquiry is not on the individual per se but on how extra-local forces hook into people’s everyday/night doings. While using some of the theoretical conceits offered in IE, it is important to emphasize that I am in no way doing an institutional ethnography. Institutional ethnographic studies begin inquiry in a persons lived-experience (actuality), developed by the studies problematic. In the case of this study, I began with a review of literature, a contradiction to IE’s ontological and epistemological shift. Conceptual frames further guide me throughout the interviews and analysis of data. An institutional ethnographer would argue that such an inquiry reinforces entrenched ways of knowing, contributing to a “blob ontology”. Despite my allegiance to IE, a study of this nature is important to further identify lines of faults to potentially be taken up by future institutional ethnographic inquiries.

thought into dialogue. Best's call applies to the multiperspectival use of ontological, epistemological, and methodological underpinnings offered by transcendental phenomenology in addition to other approaches and acknowledges that a single methodological approach does not individually allow us to grasp a complete understanding of the topic at hand. Each methodological approach has its benefits and its blind spots. This multiperspectival approach offers multiple lenses to explore the social that brings into view phenomena based on the experiences as they are lived, while not being limited to the views made visible by the conceits of one approach. In doing so, this study provides knowledge that clarifies and enriches everyday situations, events, and relationships (Moustakas, 1994) for and based on the experiences of caregivers of children with ASD.

Transcendental Phenomenology

The primary methodological approach used in this study is based on transcendental phenomenology as purported by Husserl (1970) and modified by Moustakas (1994). Transcendental phenomenology is a qualitative research strategy and philosophy that allows researchers to identify the essence of experience as it relates to certain phenomenon as described and understood by participants of a study (Creswell 2003; Nieswiadomy 1993; Orbe, 2000). Moustakas (1994) describes three core processes for deriving knowledge from this approach, all of which I will use. The first process is *epoche*¹² – a reflective process that involves “bracketing” the researchers’ knowledge and aims to allow the researcher to be open-minded (Moustakas, 1994; see also Orbe, 2000). This process attempts to suspend prior knowledge about the phenomenon under study in order to see it more clearly. While the purpose of achieving *epoche* is to provide a fairer treatment of the phenomenon at hand, bracketing one’s biases and assumptions completely is not possible (Moerer-Urdahl and Creswell, 2004; Moustakas, 1994). It is important to note that this research might be criticized for adopting the technique of bracketing because it may be in opposition to the guiding paradigm of this study (LeVasseur, 2003). In fact, if one were to compare the paradigm that guides this inquiry

¹² It is important to note that bracketing is a contentious issue in the world of phenomenology, with existential phenomenologists questioning the practice of bracketing due to epistemological and ontological reasons (LeVasseur, 2003; Caelli, 2000). To go into this debate is outside the scope of this study.

and the traditional purpose/usage of bracketing, the problem of bracketing becomes even more valid. However, the use of bracketing in this study is not to be interpreted in its traditional sense as a suspension of all prior knowledge, as that is not aligned with the social-constructivist paradigm with which the researcher approached the study. Furthermore, as Moustakas (1994: 61) points out, “the value of the epoche principle is that it inspires one to examine biases and enhances one’s openness even if a perfect and pure state is not achieved”. As such, bracketing included continuous retrospection into my beliefs, both prior to the commencement of research and throughout the entire research process.

With this said, phenomenology was chosen because of the researcher’s intent to explore and gain a better understanding of mothers’ lived-experiences. Other aspects of transcendental phenomenology including Moustaka’s second and third core processes, assisted with this purpose. The second process is Transcendental-Phenomenological Reduction, where a description of experience is provided based on meanings and essences offered by those involved with the phenomenon at hand (Moustakas, 1994), in this case caregivers of individuals with ASD. The third process is Imaginative Variation, which aims to grasp the essence of experiences (Ibid). These three processes are similar to a three-step process of description, reduction, and interpretation in an interpretive approach described by Orbe (2000: 617) to explore the lived-experiences of individuals who are often marginalized.

The most common methods used in phenomenological inquiry are semi-structured, open-ended interviews (Moustakas, 1994; Orbe, 2000). Kvale (1996: 70) describes interviews as a strong technique to make visible the lived-experiences of those who are familiar with phenomena of interest to the researcher. It is the very nature of interviewing, the sensitivity of the interview, and the one-on-one interaction between interviewer and interviewee that provide rich data that can be used to expand the understanding of experiences (Kvale, 1996; Opperman and Alant, 2002). The purpose of semistructured open-ended interviewing is to understand experiences of others and the meanings of the experience rooted in the individual (Seidman, 1991). In addition, Kelso et al. (2005) describe qualitative methods as an optimal method to study the nature of stressors and coping in caregivers of children with disabilities. This is because of the very

nature of this technique; it provides the ability to explore complex issues in the context in which they occur, without the need to quantify experience in terms of pre-defined conceptual frames.

This study, therefore, employed semistructured, open-ended interviews. The interviews retrospectively focused on the stressors, joys, and coping of parenting a child with ASD before and after placement. In addition, interviews explored the coping process of parents of children with ASD during the aforementioned time periods. By investigating the experiences of these families, and by allowing for the telling of experience that gives participants agency in the interview process, this study systematically explored people's lived-experiences based on the experience of caregivers in the context in which they occurred (Nieswiadomy, 1993). This facilitated a better understanding of lived-experiences of caregiving for children with ASD by shedding light on the experience of mothers, their life strain, strengths, social supports and how they coped with caregiving for a child with ASD who is placed outside of the home (Pearlin et al., 1981).

Procedures

In order to obtain the sample that gives the greatest insight into the topic at hand (Esterberg, 2002), inclusion criteria for this study were that mothers must have a child diagnosed on the autism spectrum as outlined in the recruitment letter and self reported by parents. While I did not ask mothers for proof of a diagnosis, the recruitment letter asked specifically for mothers of children with ASD. This was confirmed during the initial conversation with potential participants. As of the first interview, the child with ASD had to: 1) be between 6-20 years of age; 2) presently reside outside of the home for a minimum of one year in either a residential treatment facility or a residential/foster care home; 3) reside in the family home prior to placement. Furthermore, mothers had to: 1) be the primary caregiver of the child with ASD before placement; 2) reside in British Columbia or Alberta, Canada; and 3) speak English.

Mothers were the main focus of this study as they are usually the primary caregivers (Gray, 2003) and are more likely to be involved in the day-to-day struggles of caregiving. In addition, caregiving is likely to be their master status role where no other

roles exist (Gray, 2002b). Lastly, this study focuses on children with ASD because caregiving for children with ASD is more stressful than caregiving for children with other disabilities. For these reasons, mothers of children with ASD are more likely to experience severe stress than fathers or other members of the family (DeMyer, 1979), and in comparison to mothers of children with other disabilities. As primary caregivers of children with ASD, this sample provides an opportunity to explore the joys of caregiving and their possible impact on caregivers. By focusing on children with ASD between the ages of 6-20 who reside outside of the home, the most stressful situations, where parents and families were no longer able to cope so placement became the only option, is explored. Furthermore, this is an understudied population of caregivers and care receivers. Lastly, the sample criteria are limited to primary caregivers who reside in British Columbia or Alberta, Canada for two main reasons: 1) to obtain the desired number of participants, and 2) due to exigencies of time and money, travel was limited to these two provinces. This study does not control for income or education because caregiving for individuals with severe disabilities is a role experienced by women of varied socioeconomic status (Leiter et al., 2004). This study does not aim to be generalizable to a broader sample, but to gain a better understanding of the lived-experiences of this unique sample of parents.

In order to obtain specific perspectives on lived-experiences of parenting placed children with ASD, a snowball sample based on the above-mentioned criteria was employed (Rudestam and Newton, 2001). A snowball technique was chosen as the most suitable to allow individuals to volunteer for the study while protecting the anonymity and confidentiality of potential participants. Furthermore, as the desired sample might be thought of as a hidden population of caregivers, a snowball technique might be the only way to identify individuals and gain access to this group of individuals (Esterberg, 2002: 93). This purposive technique initially identified key informants, one or more persons who might know of people who belong to the sample in question. It is important to note that key informants are often friends or acquaintances of individuals sought for the study. Perhaps assisting in the development of rapport, this aspect of snowball sampling allows for individuals to vouch for the researcher and assists the researcher in gaining access to participants (Esterberg, 2002).

In order to recruit participants, different strategies were used. Parents of placed children with ASD were identified through current contacts of caregivers of people with ASD through the Victoria Association for Community Living (an organization where the researcher worked for nearly eight months, ending in May 2005). After potential participants were identified and gave permission to the referral source to be contacted, the researcher telephoned or emailed them and discussed the purpose and inclusion criteria for this study. After initial contact, if the inclusion criteria were met and if the potential participants were interested in participating in the study, a recruitment letter (Appendix A) was sent to potential participants by mail or via email explaining the purpose of the study and what was being asked of participants.

In addition, a recruitment letter (Appendix A) was posted on the Autism Society of British Columbia website (www.autismbc.ca), Autism Community Training website (www.actbc.ca), and Child and Family Counseling Association website (<http://www.cafca.ca/index.htm>) asking for people who might know of other parents of children with ASD who met the inclusion criteria for this study. The recruitment letters asked informants who might know possible participants for this study to seek permission from potential participants prior to contact information being sent to the researcher. After permission was obtained, the same procedures described above were followed. If inclusion criteria were met, potential participants were asked to participate in this study. The Society for Treatment of Autism, Calgary, Alberta (where the researcher was previously employed for six months from January 2004-June 2004) was also contacted and a recruitment letter was circulated to parents whose children reside in the residential treatment-care facility in Calgary (Appendix B). Permission was required (granted July 18, 2005) from the Society for Treatment of Autism. It was intended that these sources of recruitment would provide for access to a sufficient number of parents who might be willing to participate, or know other parents who have a placed child with ASD (Abrahamson, 1983; Esterberg, 2002).

Mothers chose the location of the interviews. All interviews took place in the homes of mothers. Prior to each interview, an informed consent form was given to the participants to sign in person at the interview site. The consent form (see Appendix C) informed participants about the intent of the study, declared the intent of the participant

to participate in the study, and assured the right to privacy (Babbie, 1992). With the consent of the participant, each interview was tape-recorded in its entirety. All participants agreed to have their interview tape-recorded. Immediately following the interview, while at the interview site, participants were requested to fill out a face sheet (see Appendix D) that included demographic information, and the place, date and time of the interview (Esterberg, 2002).

The interview began with a warming up period where rapport was developed between the interviewee and interviewer based on the suggestions outlined by Seidman (1991: 73-74) and Esterberg (2002). This initial period asked participants to talk about their family (“How many kids do you have? What are their favorite activities?”). After rapport was believed to be established and the participant seemed comfortable, the interview consisted of open-ended, semistructured questions (see Appendix E for a copy of the guiding questions). Questions explored the stressors and joys of parenting children with ASD followed by questions that explored parental coping. Mothers were initially asked to discuss the stressors during the early years of their child’s development, followed by joys and parental coping. This sequence was repeated during the time period leading up to placement and after placement. The interview ended with questions about how mothers coped day-to-day and what suggestions they have for other mothers in a similar situation. Questions were aimed at distinguishing between past stressors and joys (before placement) and more current stressors and joys (after placement). In addition, questions explored mothers’ sources of support for both parent and child, both formal and informal, the effects of ASD on the family, the one-on-one interactions between child and mother, and coping strategies and resources used throughout the caregiver’s experiences before and after placement (Gray, 2003; 1994). Due to the nature of the qualitative interviewing and structure of the interviews, ongoing appraisal was explored throughout the discussions with mothers, as they all reflected and provided insights into the dynamic nature of caregiving.

Data Analysis

Interviews were transcribed in their entirety. There are a variety of approaches to use when analyzing qualitative data. An approach originally offered by Kaam (1966;

1959, cited in Moustakas, 1994) modified by Moustakas (1994) specifically intended for the analysis of qualitative data derived from transcendental phenomenological research was used here. Moustakas (1994: 120-122) describes an eight-step process that consists of: 1) organizing the lived-experiences of participants by studying the transcripts and identifying patterns discussed by participants; 2) reducing the data into invariant constituents, which identifies the unique aspects of experience; 3) organizing the data into core themes that represent the experience of participants (clustering and thematizing the invariant constituents); 4) validating step three by reviewing the complete transcript of participants; 5) constructing an individual textural description of the experience presented by each participant; 6) based on step five, constructing a clear account of the dynamics of experience (individual structural description); 7) combining steps five and six to create a textural-structural description of each participant, that incorporates invariant constituents and themes. The last step 8) involves combining individual textual-structural descriptions of each participant into one that represents the experience presented by the group as a whole.

To assist in this approach of analyzing transcendental phenomenological qualitative data, some insights offered by Moerer-Urdahl and Creswell (2004) were followed. Initially, significant statements within each participant's transcripts were identified. To assist in this process, a three-column approach as exemplified by McNulty (2001) was used. Using this approach, data were organized into three different columns: data, coding, and comments (see Appendix F for an example of this approach). In this phase of analysis, the primary focus was on understanding how individuals viewed different aspects of their experiences as they related to the stressors and joys of caregiving and parental coping, before and after placement. The purpose of this step (step one described above), was to ground or contextualize the phenomenon in order to gain a better understanding of its distinct character (Moerer-Urdahl and Creswell, 2004).

For steps two and three, the data were broken down into themes based on the experience of mothers. The product of these steps was the grouping of statements into main themes such as stressors, joys, stressors-outcomes, and parental coping, before and after placement for each participant. In step four, each transcription was reviewed to ensure that no themes were missed. For steps five, six, and seven, a detailed description

of the experience of each caregiver as they related to the themes that emerged in steps two and three were provided. The concluding steps identified the essence of the experience by providing a detailed account of parents experience based on the entire sample (for further discussion, see Moerer-Urdahl and Creswell, 2004). It is important to note, as Moerer-Urdahl and Creswell (2004: 24) remind us, the “essences of any experience are never totally exhausted”.

The process described above is similar to the process described by Singleton and Straits (1999: 349-350). It is a three-step process that involves searching for patterns and ideas within the data and explaining why such patterns and ideas exist. This process consists of organizing the lived-experience of parents by studying the transcripts and identifying patterns discussed by participants. Ideas presented by the participants are then developed based on the lived-experience of participants. Conclusions are drawn in accordance to the lived-experience expressed by participants.

The analysis of interviews began when they were being transcribed. For instance, as each participant’s interview was being transcribed, notes were taken that identified any comments or themes that were developing during the transcription process. In addition, sticky notes were used on two single pieces of paper to record and organize thoughts throughout the entire transcription process. These approaches allowed for the start of analysis even before all of the interviews were transcribed. Furthermore, transcribing facilitated getting to know the data.

Creswell (2002: 195) suggests that validity is one of the advantages of qualitative research. This study used two strategies to check the validity of the qualitative data acquired from the participants. Peer debriefing was utilized, where colleagues were asked to read the findings section and ask questions regarding the interpretation of the findings. Member-checking was initially proposed to ensure the accuracy of the findings, where participants of the study were to be given a short summary of the findings section (if requested) and asked to look over the findings to ensure validity (see also Thorne et al, 1997: 175). Due to limitations of time, this strategy was not used. However, validity was further enhanced by conducting three follow-up interviews (by telephone) with mothers. These interviews were shorter in duration, primarily intended to check interpretations of

individuals' lived-experiences and expand upon areas that needed more exploration. The follow-up interviews served as a form of member-checking.

Pilot Study:

In preparation for this study, a pilot study (Corman, 2005b) was conducted. The pilot study explored the lived-experiences of three parents, using qualitative, semistructured open-ended questions aimed at particular stressful and joyous events and experiences. The sample consisted of three parents: Manya (a pseudonym), a single mother of four children; Tina, a single mother of two children; and Ron, a father of seven children. Participants were chosen purposively for the explorative nature of this study to include parents with both typical and atypical developing children. Manya had four typically developing children, Ron's child had Attention Deficit Hyperactivity Disorder, and Tina's child had Asperger's Syndrome, a disability on the autism spectrum.

The main purpose of conducting this pilot study was to test issues of qualitative research. The study informed the development of the research design used here. Issues such as the time allocation required and development of rapport, structure of interviews, and issues involved with data analysis were also explored. These issues are briefly discussed below.

Time allocation of interviews and development of rapport

Based on the findings in the pilot study, it was concluded that the time allocated for each interview, between one to two hours, would be sufficient to explore issues addressed. It was also concluded that sufficiency and saturation of information would be reached (Seidman, 1991).

Esterberg (2002) describes rapport as the process whereby trust is developed between interviewer and interviewee. One purpose of the pilot study was to address issues of rapport development. It was concluded that a good way of doing this was to interview participants with whom the researcher had varying degrees of prior-existing relationship. Similar to the pilot study, all parents interviewed for this study had varying degrees of prior-existing relationship with the researcher, whether it be from the researcher working with their child with ASD at the treatment-care centre in Alberta and coming into contact with them at certain points in the past before the researcher

commenced graduate studies or not knowing the researcher at all. It was believed that the sample for the pilot study would provide useful insights in how to develop rapport with different people. As such, a mother (Tina) who was a colleague of the researchers at Victoria Association for Community Living who had been known (prior to the interview) for roughly a week, a mother (Manya) who was a colleague of the researcher at university who had been known for three years, and a father (Ron) who is a family member and is very close to the researcher. All three interviews began with the same rapport developing questions that asked "Can you begin by telling me some things about your family? For instance, how many kids do you have? How old are they? What are their favorite activities?" While this line of questioning was awkward for the family member interviewed, these opening questions worked well for the other two participants. These initial questions allowed a start in a way that was not devoid of context (Hollway and Jefferson, 1997). In addition, these opening questions provided a logical entry into the questions outlined in the interview guide that focused specifically on parents' lived-experiences as they relate to the stressors, joys, and parental coping for their child with ASD. It is important to note that rapport development started prior to meeting any participants in person; whether it was speaking to them on the phone or via email, developing rapport began from the initial contact with participants.

Structure of Interviews

A main purpose of the pilot study was to test a specific questioning sequence to see how parents recalled their experiences as they relate to the stressors and joys of caregiving. It was decided to begin by asking questions about the earlier years of the child's development, followed by questions about the later years. This sequence of questioning (from early years to later years) provided parents with what seemed to be a relatively easy time recalling their lived-experiences as they relate to the stressors and joys of having a child with ASD and parental coping. It was decided that this sequence would be used in this study.

The pilot study also informed the development of the interview guide used for this study by allowing the researcher to gain critical feedback about the interviews and questions asked. For instance, following the rapport-developing question, the researcher

asked Manya a very long and complex first question about the stressors of caregiving during the earlier years of her child's development. She had no problem telling me "that's a pretty big question I think Mike". The feedback provided during and after the pilot interviews allowed the interview guide to be improved prior to interviewing participants for this study. Furthermore, the pilot study allowed for the development and practice of asking follow-up questions that expanded on caregivers' lived-experiences.

Analysis

The pilot study provided the opportunity to experiment with many different data analysis techniques. After the interviews were transcribed, the researcher inspected the data thoroughly and then organized the data using the three-column approach. It was concluded that the three-column approach for data organization, where the data is separated into three columns (Data, Coding, Comments – see Appendix F), was helpful in the inspection and organization process involved in data analysis. It was decided to use the three-column approach in this study to assist in the data analysis phase because it was helpful for the researcher in the pilot study. This step of data analysis was followed by a step that involved reducing the data. This step posed the most difficulty for the researcher. As such, case summaries (Reitsma-Street, 2004) using the constant comparative method (Ristock and Pennell, 1996) were piloted. However, the researcher was "jumping the gun" because summaries consisted of both the reduction of data and the transformation of data. The researcher had to backtrack and take a different approach, attempting to organize the data by creating a "semi-findings" section where findings for each participant was reported. Both approaches, despite leading the researcher astray and taking up time and energy, allowed for a thorough inspection of the data.

Similar to Esterberg and Longhofer (1998: 195), the reporting of the findings for the analysis attempted to allow participants to "speak for themselves...solv[ing] the power issues involved in the relationship between researcher and researched". The researcher also piloted a three-step analysis process described by Singleton and Straits. This process, similar to the one used in this study (as mentioned above), consisted of organizing the lived-experience of parents by studying the transcripts and identifying patterns discussed by participants. Ideas presented by the participants were then

developed based on the lived-experiences of participants. Conclusions were drawn in accordance to the lived-experience expressed by participants.

Conclusion:

This chapter outlined the research design of this study and the steps to be taken to explore the lived-experiences of caregivers of children with ASD. I explained how this study is exploratory and descriptive in nature. I discussed the use of a qualitative research design that is interpretive, constructivist in its orientation. As well, I outlined transcendental phenomenology as the dominant qualitative method that guides data collection and analysis of this study. I now turn to the findings.

Chapter IV

The Findings:

I just have the one kid, Sam, and he's now eighteen years old. And his favorite activities right now, it's just driving in the car, which is kind of hard on us, and he likes swimming...So there's just me and my husband and Sam, and Sam doesn't live with us anymore... (Sarah)

The Findings chapter is organized into six sections based on themes discussed by participants. The sections are separated into five distinct yet overlapping time periods. These time periods emerged through analysis. This is outlined in Table 4.3. **Section 1** reports on parents' lived-experiences during the early years prior to placement. **Section 2** reports on the time leading up to mothers' inability to go on and their "decision" to place. **Section 3** reports on the time leading up to placement, after the decision was made. **Section 4** reports on the period immediately following placement that is termed the stressor-period. **Section 5** reports on the time after the stressor-period subsided. **Section 6** concludes this chapter with a reflection from mothers on their entire caregiving experience.

Table 4.3 – Chapter Outline

Section 1- Before Placement	Section 2 – Leading up to parents' appraised inability to cope	Section 3 – Leading up to the child leaving the home	Section 4 – After Placement – stressor-period	Section 5 – After Placement – after the dust settled	Section 6 – Mothers reflections on their overall experience
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Each section and its corresponding parts is not exclusive; while the stressors, joys, and parental coping are discussed separately and at different time periods of a parent's lived-experience, all parts and sections inevitably overlap. The stressors or joys, unless specifically mentioned have not stopped occurring. Lastly, stressors and joys are stressful and joyful because of the context of the mother's lived-experience in which they occur. As a result, difficulty arises when trying to separate and detach the stressors and the joys from the stressor outcomes. For the purposes of presentation, I try and isolate the stressors and joys of caregiving for a child with ASD as described by mothers. However I am not able to do this in every case. When this is the case, I make note of it. Before

reporting on the findings of this study, it is important to first introduce readers to the mothers who participated in the study.

The Mothers:

Mothers were the primary source of data. Demographic information was obtained immediately following the first interview and is summarized in Tables 4.1 and 4.2. Mothers were asked a range of questions, including their age, work status during the time when their child lived at home, marital status, age of child at placement, age of child at the time of the initial interview, type of diagnosis (self-reported), type of placement, number of years the child had been out of the home, gender of child, and number of other children living with the family while the child with ASD was living at home. Also, to gauge the socioeconomic status of participants, mothers were asked to give a range of their annual income.

Nine mothers participated in the study. The location and time of the interview depended solely on the preference of participants; all took place in the homes of mothers. Interviews lasted on average 2.24 hours with a range between 1.5-3 hours. The amount of time for interviews and the sample size is consistent with past interview studies (Kvale, 1996: 102), and met the criteria for sufficiency and saturation of information, in addition to meeting the exigencies of time and money (Ambert et al., 1995; Seidman, 1991).

Table 4.1 – Demographic Information

	Average	Range or actual numbers
Length of interviews	2.24 hours	1.5 – 3 hours
Age of child at time of interview	14.4 years of age	8-18 years of age
Age at Placement	11 years of age	6-15 years of age
Years out of home	3.4	1-10
Gender (F-M) ratio of child with ASD	--	2-7
Age of mothers	46 years of age	35-62 years of age
Mothers' work status during caregiving years	--	4 – fulltime 3 – part-time 2 – unemployed
Mothers' marital status	--	7 – married 1 – common-law 1 – single parent
Other children living at home during the caregiving years	--	5 – mothers who had one or more children besides child with ASD 4 – mothers who had only their child with ASD
Province (actual numbers)	--	6 – British Columbia 3 – Alberta
Rural/Urban (actual numbers)		2 – Rural (2 BC) 7 – Urban
Income	--	Range – 30,000 – 40,000 – 100,000+

Table 4.2 – Type of Diagnosis (self-reported) and Type of Placement

Participant ¹³ :	Diagnosis of Child:	Type of placement:
#1 – Anne	Pervasive Developmental Disorder – not otherwise specified	Residential Group Home
#2 – Sarah	Autism, Landau-Kleffner	Residential Group Home
#3 – Tammy	Autism, Tourette's, Obsessive Compulsive Disorder	Residential Group Home
#4 – Mary	Autism (Moderate-Severe), Mental handicap	Residential Group Home ¹⁴
#5 – Deb	Autism Spectrum Disorder - Classical Autism	Foster Care
#6 – Jess	Pervasive Development Disorder (PDD), Epilepsy	Residential Treatment-care Facility
#7 – Shelly	Autism, Seizure Disorder	Residential Treatment-care Facility
#8 – Meg	Autism, Developmental Delay, Seizure Disorder	Residential Group Home
#9 – Lisa	Downs Syndrome, Autism, Pervasive Developmental Disorder – not otherwise specified (PDD-NOS)	Residential Treatment-care Facility

Six of these mothers lived in British Columbia while three lived in Alberta. Two lived in rural settings while seven lived in urban settings. The average age of participants was 46, with a range between 35-62 years of age. Two of the mothers had a female child

¹³ In order to protect anonymity and assure confidentiality, all names of participants and identifying features have been changed.

¹⁴ The first option given to this mother was foster-care. When that did not work out, her son was placed in a group home.

with ASD and seven had a male child with ASD. The average age of the child at placement was 11 years old, with a range between 6-15. The average number of years the child had been placed at the time of the first interview was 3.4 years, with a range between 1-10 years. During the at home caregiving years, four of the mothers were employed full-time, two were stay-at-home mothers, and three were employed part-time. At the time of the first interview, seven out of the nine mothers were married, one was a single parent and one was in a common-law relationship. Only one mother's marital status changed from the at home caregiving years to the time of the first interview. Mary's husband passed away during the years when her child with ASD was living at home. She has since remarried. During the caregiving years at home, five mothers had one or more children living at home besides their child with ASD; four mothers had only their child with ASD. Family income ranged from \$30,000 – 100,000+. One mother responded middle class while another mother preferred not to answer this question.

All diagnoses reported by mothers were on the autism spectrum. Additional diagnoses included: Landau-Kleffner Syndrome, Tourette's, Obsessive Compulsive Disorder, Mental Handicap, Epilepsy, Developmental Delay, Seizure Disorder, and Downs Syndrome. It is important to note that ASD is often accompanied by co-occurring psychiatric and physical health conditions (Seltzer et al., 2004; Gray, 1994; Fombone, 2003). As of the first interview, three mothers reported that their child with ASD was currently placed in a residential treatment-care facility setting, five were placed in a residential group home setting, and one was placed in a foster-care setting.

Section 1 – Parents' lived-experiences during the early years prior to placement:

This chapter begins with a focus on how mothers experienced stressors and joys, and how they coped during the period prior to the idea of placement and their child eventually leaving the home. Mothers experienced a multitude of stressors and joys, and positive and negative outcomes during this time. They also described the ability to cope with the demands of caregiving (compared to being unable to cope leading up to and immediately following placement). Most of the stressors, negative outcomes, and parental coping discussed by mothers were consistent with past research findings. On the

other hand, some of the stressors and the positive side of caregiving discussed by mothers illuminated an under-studied aspect of their caregiving experiences, including how joys impacted their stress-coping process. Therefore, I provide only a brief description of the themes consistent with past research. I spend more time on the findings as they relate to the joys and positive outcomes experienced by caregivers during this period.

This section is separated into four parts. Part 1 begins by reporting on the findings as they relate to the stressors and negative outcomes, followed by the more joyous side of caregiving. I discuss events that were joyous for mothers, events that were both stressful and joyous, and how these events impacted mothers' caregiving experiences. Parental coping is discussed in Part 3. While parents mentioned a variety of resources and strategies that helped them cope, three primary ways emerged. Concluding this section, Part 4 illustrates the concept of ongoing appraisal, depicting the more dynamic nature of parents' lived-experiences.

Part 1 – Stressors:

He was born in 1989 and seemed like a normal healthy baby...As he grew, he just wasn't developing normally and he sort of started making sounds as though he was going to start and talk and then he quit making sounds and would just sort of sit in a corner turning pages of a book; was just quite withdrawn...typical signs of autism, like never made eye contact, didn't kind of associate much with people, used our hands as tools; if he wanted something he would put your hand on the fridge door. If he was hungry that was his way, without making eye contact or anything. Just sort of like the disembodied hands as tools. It was quite odd. (Meg)

There is no doubt that caregiving for an individual with ASD is demanding. Mothers all reported multiple stressors and negative outcomes derived directly and indirectly from their caregiving role. Based on thematic analysis, five major stressors were identified that derived directly from their caregiving role. These stressors included: their child's autistic traits, the receipt of a diagnosis on the autism spectrum, other physical and developmental conditions, stigma from the general public and professionals, and social supports. Because of the difficulty in empirically separating stressors from their outcomes, some of the stressors discussed below incorporate their outcomes. However, I end this part by isolating some of the negative psychosocial and behavioural outcomes discussed by mothers.

As mentioned previously, ASD is characterized by a triad of impairments in the areas of communication, reciprocal interaction, and restricted, repetitive behaviours and interests (Seltzer et al., 2004). While individuals on the autism spectrum vary in severity of autistic traits, by definition of the disorder, all individuals present a range of these traits. These traits have the potential to act as stressors for caregivers. For example, mothers described a variety as stressors, including: multifaceted maladaptive behaviours, such as both physical and verbal aggressions towards parents and siblings, their child not sleeping and feces smearing; sensitivities to certain stimuli; perseverations “like dumping gallons of milk” (Sarah); having limited interests; and the lack of ability to communicate with their child. Most of these stressors were associated with not understanding what was wrong with their child.

Other stressors included the diagnosis process of ASD (Corman, 2005b; Kelso et al., 2005) and the actual receipt of a diagnosis on the autism spectrum. For some, the receipt of an ASD diagnosis represented the loss of a child that was or could have been. Anne explained, “the day that I found out [I was floored] because there’s nothing like that in my family, and we’ve always been high achievers...and I don’t know where that [diagnosis] came from”. Similarly, Debra explained:

...And then the realization that developmentally there were delays and something underlying that, which was the autism. It meant that he was not a typical child for life instead of just for his childhood...It was frustrating. Yeah it was, it was sad, it’s pretty devastating, to have a child who’s not typical.

Mothers talked about the diagnosis process (starting with a mothers’ perception of a problem) leading up to the receipt of a diagnosis as a time of transition that represented the loss of a child that was. Before the perception of a problem, mothers had a “dream” that their child would grow up and be a successful “contributing member of society” (Mary); beginning with the perception of a problem and culminating with the receipt of a diagnosis, mothers began to realize that their child was not going to be normal. Debra, for instance, described how, after the receipt of a diagnosis, she contemplated her child’s future “under a diagnosis of autism”. She came to the conclusion that “he’s never going to be independent”.

Third, ASD is often accompanied by other physical and developmental conditions. Stressors arose from these conditions. Debra’s child, for instance, had

difficulty breathing during the early years of his development. As a result, both mother and child “were in and out of hospital a lot, which was very stressful...I think that the physical stuff was definitely a challenge”. Lisa’s child had a dual diagnosis of ASD and Downs Syndrome. Her child had “medical issues that would be specific to Downs syndrome: he has a heart condition, he had visual problems, he had to wear glasses... so the medical stuff was definitely the hugest stress in the beginning”.

Stressors also emanated from the general public and from professionals and government workers in the form of social stigmas, primarily in the form of courtesy stigma (see Gray, 1998; Gray, 2002b). In this case, children with ASD are stigmatized due to their behaviours and other qualitative impairments, which may result in the mothers also being stigmatized through affiliation. It is important to note that caregiving for a child with ASD falls under the category of a discreditable stigma (Gray, 2002; 1998) because ASD is an invisible disability that can often be concealed. For instance, even when a child with ASD is misbehaving or displays what can be termed autistic traits, others might not associate these behaviours with a disability and may attribute them to ill-parenting. For Tammy, it was “very stressful...dealing with the general public if your child’s having a meltdown and they don’t understand why...I’ve had some more severe experiences when he was older that were really traumatic from a parental point of view with dealing with a public that’s not very understanding”. Part of this stressor arose when people imposed their own beliefs onto mothers as a failure to “fix” their child’s “handicap”. Mothers explained how others judged and stigmatized them for not being able to make their child behave and “act normal”. Debra explained:

Social stigma...When a child is ill or ill behaved for sure it’s hard not to worry about what people are thinking...and even when they’re just down right rude...Just a few weeks ago I was in the lineup at Superstore and Ben was melting down and this old woman came around us and went in front of me ‘cause we hadn’t moved up quite quickly enough in line for her liking. So yeah people actually can be really rude, that never ceases to amaze me. There’s that and plus...they actually come right out to discipline or speak to your child...He doesn’t have a flashing label on his head that says I have autism, mommy’s dealing with it, back off (laugh).

In addition to experiencing stigma from the general public, Tammy experienced stigma from professionals. She described the health professionals she came in contact with as an

“old boy’s network” that had “old school attitudes about people with autism”. As a result of this atmosphere, Tammy had difficulty finding professional help “who really believe in what you’re saying”. Tammy went on to explain her government social workers’ actions, revealing stigma associated with professionals; “our social [worker] had never been to our house...never met our son before [she] made a whole bunch of judgments...”

While most research has focused on the positive side of social “support”, what follows is a depiction of how social support or lack of support, both formal and informal, can act as a stressor. Meg, for instance, explained how the formal support her child was receiving placed added demands on her.

...I had to take him to the city, stayed down there for two weeks at a friend’s house, which is [in the northern part of the city] and then drive to [the southern part] for my session in the morning, so it’s like an hour drive. So I do the session in the morning and then I’d hang around until the session in the afternoon and...I went a lot to the McDonalds which has this carousel...But it was a huge deal to go to the city and I don’t know what [my husband] did with [my daughter], like he stayed home with Sue while I was down there and ran the [business].

Another mother explained how she had to go to “constant meetings” because of the formal services her child with ASD was receiving. These meetings resulted in added demands where “there just never seemed like any time just to be” (Mary). Other parents explained how government policies in British Columbia that were intended to help parents cope with the demands of caregiving placed added demands on them instead. In order to access services and supports made available to families of children with ASD, Debra had to become an employer. As a result, she described the government as “not getting top marks for initiating a smooth transition [from pre to post ASD diagnosis]”. In fact, she described this stressor as adding “to the work load [and] mak[ing] it several times more difficult than it probably could have been, should have been”.

Others viewed the actual support they were receiving in a negative light. This was Jess’ experience when her child with ASD was in school (which can be viewed as a form of support). She had to constantly go to the school to support the individuals who were caring for her child. In addition, she worried about her child’s well being while she was at school. She described her experience in the insert below:

Basically [I] was down there most of the time because they were constantly phoning me saying, ‘well she’s scratching me. She’s doing this, she’s doing

that'... And they just couldn't handle it. So they were calling me, we [lived nearby] the school so I was over there... I always worried that somebody would hit her or things like that, or they'd loose their temper because that's a big thing, when a kid's acting like, you worry ... But most of the day she'd be coming home [from school early]...

Some parents simply could not find any services to support them or their child with ASD. Jess explained how she "couldn't get anybody to look after her [daughter] because they couldn't handle it". As a result, she had no one to provide her with support in her rural community:

They'll [the British Columbia government] give you the money to find somebody, but try and find somebody, you can't. They did a search in [the Valley], for respite or some kind of a part-time place that we could take Kate to give the family a break, they couldn't find anybody.

Stressors also emanated from informal supports. Meg explained how family and friends were trying to be supportive by giving her advice but did the exact opposite. As such, Meg viewed these informal supports in a negative light, as pressure to be a "normal" family and the need to "fix" her child with ASD:

...There's enough information out there that a kid could do so much better if he did all these things [like] auditory integration, swimming with dolphins, feed him this, don't feed him that, give him these vitamins ... People are constantly forwarding [ideas] and trying to be helpful and telling you what you should do ... And some of those things we did and some we just thought were crazy and we didn't do them. I'm just explaining I think how much pressure there is on a parent of a kid that's that dysfunctional.

Shelly had a similar experience with her mother:

Well it was intrusive a bit...It's kind of in those times of stress that you kind of rub up against the personality aspects of, in this case, my mom. [She was] there always but in this situation it makes it really hard. I wanted her just to listen to me but she felt she had to fix everything. The more she fixed things the more kind of disabled I felt as a mom and that kind of thing went on a fair bit.

These added pressures to "fix" their children with ASD contributed to mothers viewing informal support from friends and family in a negative way, further contributing to the mothers feeling like failures because they were not able to "fix" their child.

The majority of stressors described by parents consisted of those emanating directly from the caregiving role, as discussed above. Stressors also emanated outside of

the direct caregiving role. These types of stressors included: being or feeling like a lone parent, having additional children living at home in addition to the child with ASD, and being employed outside of the home. Similar to the stressors derived from social supports, these stressors placed added demands on mothers.

One of the lone parents who participated in this study described the added demands of being the sole provider for their child. These added demands derived from her multiple roles. Debra explained:

[I] need to be mother, father, chauffeur, cook, disciplinarian, cleaner, educator, playmate, reader. If you're a single parent you wear all those hats. If I had a partner a certain number of those things hopefully, even half of them (laugh) ... would be taken on by someone else, or shared.

Mothers who were either married or had partners expressed similar sentiments of feeling as if they were a lone parent. This applied to those whose partner was either employed outside of the home or was not present for a significant amount of time (Lisa and Anne) and by mothers whose partner was unable to provide any care due to a physical illness (Tammy and Mary¹⁵).

Mothers who had additional children in the household, either older or younger than the child on the spectrum, voiced this as a stressor, either as a result of sibling conflict or the added demands of caregiving for additional children. For instance, Meg described the added demands of caregiving for two young children, her daughter Sue and her oldest son Roy with ASD. She said, "when [Roy] was little, the traveling wasn't so bad, it's just like after we had Sue, it got more difficult 'cause then there's two kids". For Meg, having an additional child resulted in added demands, which made it "tough" on her. In addition to increased demands, the family dynamics changed with an additional child; "[after Sue was born] Roy couldn't stand the noises his sister made and would run screaming from the room and try to get out of the house and we were trying to keep them in separate rooms, which was pretty tough, just trying to manage all that". Having additional children for Anne resulted in sibling conflict between her child with ASD and her other non-ASD children. She explained how her child with ASD would "poke his siblings, hit his siblings... he just wouldn't be able to keep his hands to himself". These

¹⁵ Mary became a lone parent after her partner passed away due to a physical illness. Mary also described added demands as a result of being a lone parent.

“interactions between Tom and his siblings” resulted in sibling conflict and acted as a stressor.

For many of the mothers who were employed outside of the home while caregiving for their child with ASD, employment acted as a form of respite. It provided them with a break from caregiving (described below). Two mothers, however, said otherwise. Despite her workplace being “supportive” when her child was diagnosed with medical problems and ASD, Debra’s career was a “real challenge”. She struggled between her desire and need to work and her desire and need to stay home with her child. Though Meg did not express employment as an additional stressor, she described work as “all the same” as caregiving because she worked from home. Work, therefore, did not act as “an escape” from caregiving. She explained, “I might have to go down and see patients or do some work down there [where the office is located], I’d do the books too, but then I’d have to come back up and just sort of back and forth, it’s all the same”. For these two mothers, it was the context and nature of employment that acted as an additional stressor, impacting their experience of caregiving.

Depending on how events are appraised, the context of events, and the circumstances between the person and her environment, stressors can lead to neutral or irrelevant outcomes, or to positive, negative, or co-occurring positive and negative outcomes (Folkman, 1997; Lazarus and Folkman, 1984). Using the stressor of a child’s lack of communication to exemplify this point, the outcome would be irrelevant for the mother if she was not concerned about this stressor. On the other hand, a negative outcome would occur if the child’s lack of communication resulted in the mother worrying about the child and being anxious about his development. A positive outcome might result from this stressor if it led the mother to find support. A co-occurring outcome would occur if the stressor led to the mother worrying on the one hand but fostered a sense of closeness to her child on the other hand. When asked to discuss the stressors of caregiving, parents did not discuss events that had the potential to be stressful but were appraised as irrelevant (if an event was irrelevant, it was not appraised as being taxing on the individual and therefore was not stressful (outcome)). In other words, mothers only spoke of negative, positive, or co-occurring events. Therefore I do not focus on irrelevant events. Because I focus on the joys of caregiving and the co-occurring

positive and negative outcomes later, what immediately follows are some negative outcomes that mothers experienced.

Negative Outcomes:

All mothers experienced many negative outcomes associated with the stressors they reported. These outcomes were consistent with past research findings and consisted of either psychosocial, behavioural/physical outcomes, or a combination of the two. Psychosocial outcomes refer to the subjective component of caregiver burden, whereas behavioural or physical outcomes refer to the objective component. Chappell et al. (2007) explain that objective burden consists of such things as disruptions in daily routine, employment and health. On the other hand, subjective burden refers to emotional reactions to situations reported by individuals, such as low morale, anxiety, and depression.

Many mothers talked about symptoms of depression resulting from the demands of caregiving, such as depressed mood, pleasure-loss, disturbances in sleeping patterns, appetite disturbances, listlessness, difficulty maintaining concentration, low self-esteem, agitation and psychomotor retardation, and suicidal thoughts (see Chappell et al., 2007). For instance, mothers reported not being able to “think right” (Jess), having suicidal thoughts, being tired, cranky, and unhappy (Lisa). Some described having difficulty maintaining self-esteem and “belief in yourself as a competent and responsible parent” (Meg), while others expressed “feelings of not belonging” and isolation (Mary and Lisa). Other mothers “thought we did something wrong” (Sarah) and blamed themselves for their child’s disability. Mothers also felt “terribly guilty” (Lisa) that they were unable to give their non-ASD children more attention.

Other mothers expressed resentment and anger. For instance, Shelly described why she resented her daughter with ASD because it was her daughter that made her rely on other people for help, when all she really wanted to do was “be very independent...[Her child with ASD] just made it impossible for me to do it on my own” (Shelly). Others felt resentment and anger towards the formal support system (Tammy) for making it so difficult to access supports and services.

Some mothers said they were “constantly anxious” (Lisa). Symptoms of anxiety mostly manifested in worrying. Mothers worried about their child’s personal well-being and safety and the well-being of their non-ASD children as a result of certain autistic traits, such as aggressive behaviours. One mother worried about the hygiene of the household as a result of her child smearing feces (Lisa). Other mothers, like Debra, explained that going to work “absolutely increased the stress...and the guilt” because of “worrying about leaving [her child with ASD] behind with his needs.”

Perhaps related to anxiety, mothers were constantly on guard, where “so much time was spent trying to make the great saves because he was slamming a door, he was pouring a whole jug of red Kool Aid on five pounds of sugar that he just put on the floor and then smearing it over the walls...it was just one thing after another” (Lisa). Being on guard included having to “be aware all the time of your surroundings, especially if you’re out in public with him because something could startle him that you might not be expecting” (Tammy) and “having to watch her [child with ASD] every second” (Jess). Others explained how they were always “on-call. ...There’s no backup... every time anybody’s sick, anybody has to go out of town, anything changes, anything happens, it’s my problem” (Meg).

Exemplifying negative behavioural outcomes, mothers also described how their activities were limited because of their child’s behaviours (as described below, limiting or modifying outings can also serve as a coping strategy). These limitations led to mothers and families being socially isolated from the outside world and from each other. One mother, for instance, was “scared even to talk to anybody” on the phone because her child with ASD would go “absolutely crazy, screaming her head off” (Jess). For some, their child’s behaviours “would make it absolutely unbearable that we couldn’t take her out anymore...we couldn’t do nothing because she was a hundred-percent, we had to look after her” (Jess). Another mother explained how “[We] couldn’t go anywhere as a family, that was the other huge stress...everything was out of the question; we couldn’t go to Christmas plays, everything was divide and conquer.” (Lisa). Other mothers manifested outcomes in a “really physical way” (Meg). These physical outcomes were apparent in Meg who was “in [muscle] pain most of the time”, which eventually became “incapacitating”. Similarly, as a result of her child not sleeping, Mary was “graying with

lack of sleep". As Sarah explained, "you don't even know what you're doing after three days [of no sleep]. It was really hard."

All partnered couples also experienced marital discord; however, this group of mothers reported no divorces¹⁶. This discord was associated with the stressors of caregiving for a child with ASD and a lack of services and supports. Sarah explained:

Well, there were times when my husband and I wouldn't see eye to eye on things and I think things that would normally have worked out, if you didn't have all the stressors of raising a kid like that... I left twice or three times...just because it was just too much like, living was too much; he (my husband) wasn't understanding, there was a lot of stress in the marriage and instead of you know taking a step back... When you have a kid that's hanging on, that is pouring the milk down the sink and peeing in the bedroom, (sigh) you don't come back to that person and say 'oh, it's ok now' you know, you're angry, you're angry with what's happening with this but you're not going to take it out on the kid, so you're going to take it out on each other...

On a similar note, one of the lone parents attributed being single to the demands of caregiving for her child. Debra explained, "I was exploring a relationship with someone but the challenges of caregiving made it really hard to focus on that..."

Mothers also felt as if they were "swimming upstream" (Mary) due to an inability to access services as a result of either the length of the diagnostic process and not receiving a diagnosis of ASD early on, or not understanding what was wrong with their child. Constantly having to fight to gain support for themselves and their child with ASD, some "eventually stopped" using the support because of the stressors associated with it (Tammy).

Exploring the stressors and negative outcomes involved in caregiving for a child with ASD is an important aspect of parents' lived-experiences. In fact, mothers had no problems discussing the stressors involved in caregiving before, during, and after placement, perhaps suggesting how pervasive stressors were. However, stressors and negative outcomes are not the only aspects of caregivers' experiences. What follows is an examination of the other side of caregiving – the joys of caregiving.

¹⁶ Sarah, however, mentioned that she left her husband two or three times "because it was just too much. Living was too much; he wasn't understanding [and] there was a lot of stress in the marriage".

Part 2 – The Joys of Caregiving:

When you have joys with a child that's really handicapped, they're really little things that probably nobody else would be doing back flips over. (Lisa)

Well they (the joys) kept me going...it wasn't all negative. It kind of gave me hope to continue on, like every day is a new day kind of thing... It gave me a reason to get up in the morning so I wouldn't be waking up going 'oh no, I have to deal with another day' sort of thing...any time you have any kind of joy or positive feelings then that ... just gives you a really good feeling that you can continue over the next period of time...If you're having a good day or you're experiencing some joy then it's going to make me feel good, happy about things, and then that's going to continue on to the next part of the day or the next event... (Anne).

The joys of caregiving occur when an experience is appraised in a positive light. Parents were asked to describe the joys of caregiving prior to placement. When the conversation turned to the more positive side of caregiving, I encountered a variety of initial reactions. Some mothers were able to speak immediately of the joys they experienced, while others were surprised by the question and had to “think about [it] for a minute” (Lisa). One mother immediately responded, “Well, there wasn't much joy” (Meg). Perhaps these latter reactions occurred as the result of a poor transition from the stressor section that occurred before it. Perhaps a more accurate explanation is that some mothers experienced difficulties because they were not used to talking about the joys, especially during times of stress and especially during their past experiences with researchers and practitioners alike.

Despite the initial difficulty for some, all mothers were able to recall and talk about a multitude of joys during this time of their lives. All parents expressed the joys prior to the placement of their child as pockets of joys because they were “kind of few and far between” (Anne). The joys that derived directly from their caregiving experiences included: knowing or discovering what is wrong with their child times of perceived normalcy (their child developing, seeing their child happy, and during times devoid of negative autistic traits), and unique and/or positive personality traits of their child.

All parents expressed a sense of joy from understanding what was wrong with their child. This joy impacted mothers because it gave them a sense of control over their

situation. For some, the receipt of a diagnosis on the autism spectrum was not a stressful experience but a joyful one because they had been fighting for answers for such a long time. After receiving a diagnosis, one mother described how “all of a sudden you know...because up until this point everybody’s been asking me ‘why is he doing this? What’s he doing? And I’d be going ‘I don’t know; I don’t know’. I really had no answers for anybody” (Lisa). With a diagnosis, answers started “coming out” (Anne). With these answers, joys arose out of knowing and understanding what was wrong with their child. Debra explained:

I’m very much a doer and so when you have a diagnosis, then you can look at putting the pieces together to move forward and do something, especially I hear so much about early development and early intervention. It was right around the time that the money was being made available for early intervention and I didn’t want to waste a minute, especially knowing that that money would dissolve when he was six.

In addition to gaining a sense of control from gaining insight into what was wrong with their child, receiving a diagnosis of ASD also had a behavioural impact on mothers. It allowed most mothers to gain access to specialized services and supports for their child. Also, it allowed mothers to finally set out a pathway of care for their child. The ability to take action was joyous because they now were able to help their child and receive supports¹⁷.

Unfortunately, with a diagnosis on the autism spectrum, parents are still left in ambiguity; because of the nature of the disability, they do not know how much their child will develop in the years to come. As such, when their child started to make developmental gains, it was joyful. For example, seeing her child progress in developmental areas, such as “when he started to speak”, was a joy for Anne; she was “very pleased”. Similarly for Sarah, when her child succeeded in learning new tasks; “Oh yeah, his success still makes me feel good, no matter what. Like I remember when he learned how to wave good-bye. That made me cry that day (laugh)”. Others mentioned the “little milestones that parents take for granted, I think are tremendous” (Tammy). Debra explained, “[It]...was hugely satisfying. It makes it all worth it when you start to see a little bit of language or a behaviour, or a skill emerge”. For Lisa, it gave her hope

¹⁷ While mothers retrospectively described finding out what was wrong with their child as joyous, this time might be better characterized as a time when parents were more relieved than joyous.

for her child's future, impacting the concerns and worries she had for her child's future. Lisa went on to explain, "I think...a little bit of joy with a child that's seriously handicapped goes a long way. It gives you a lot of hope...Those are the things that keep you going...a little bit of joyful experience gives you...the ability to go on."

All mothers experienced joys from seeing their child happy. While this might seem like a common joy experienced by all parents, it is important to contextualize this joy in that many mothers viewed their child as being chronically unhappy; Anne put it best, "just to see him happy, because all through his life he's lived either withdrawn or anxious, or afraid of doing things". When mothers saw their child happy, they were especially happy. For example, joy arose for Anne from seeing her child enjoying his favorite activity;

You see this bright-eyed little boy at the top of the slide, that was his favorite activity was going down the slides. So when you see him at the top of the slide with this big grin on his face, those kinds of times were really exciting for me...I just knew that he enjoyed that.

This made her feel "really good...That is sort of what we hope our kids are going to feel". Similar to Anne, when Lisa and Meg saw their child happy, they also experienced happiness; "when he's happy and having a really good time, then I'm happy. It's like I'm just a normal parent" (Meg). When mothers saw their child as "normal" or "typical", they were happy.

Similarly, joys were usually present during times devoid of negative behaviours (negative autistic traits), times we might think of as being "normal". For instance, on days when Lisa's child "didn't throw his food... [or] didn't have any feces smearing in the bathroom", were joyous times for her. Similarly, Anne experienced joys during times when "he hadn't pinched another child or hit another child...So any time he was cooperating...times that he was being and not bothering anybody...If I heard that he sat for five minutes in his desk, or he sat in circle time without poking the next person..." During these times, Anne expressed an outcome of being "really happy".

Despite many of the difficulties mothers experienced while spending time with their child, all mothers also experienced joys when with their child with ASD. Sarah and her child would go swimming together and go down to the beach to spend time together. Her child "loved it" and always "liked hanging off me", and she described how there

were so many “nice times” that they spent together. Tammy described an outcome of feeling “just connected” to her child because of the time they spent together, specifically “the caregiving part...being hands on physically connected”. She talked about how she “really enjoyed” the connection she had with her child, “we’re connected on a different level”. This led Tammy to conclude:

I guess having a child with autism, you connect with them on a completely different level than I think you would with other children because you don’t have language. He’s also mostly nonverbal so physical connections are really important; it’s the way you communicate that’s beyond words I guess, so I think that’s part of it.

All mothers also expressed joys derived from positive personality traits of their child, including their child being “real sweet” and showing affection (Sarah, Shelly), their child being a “very warm individual... We were blessed that way I guess; very cuddly, quite attached to your close family members” (Tammy). Other joyous personality traits included their child being “very funny, like she’s got a good sense [of humor] ...she’s quite a little monkey” (Shelly), and their child being “a very good natured kid...he still has a happy disposition” (Debra).

Mothers also expressed joys derived from time spent outside of the direct caregiving role and when their child and themselves developed bonds with others. They included: mothers spending time with their non-ASD children, and mother and child developing bonds with others. Similar to other joys that were discussed above, these joys were “few and far between”. For instance, mothers who had other children expressed joy when they spent time with their non-ASD children. Anne for instance “would take the kids out to the odd movie or one of my daughters out to a musical if I knew that my husband was home...”

Due to the nature of the disability, ASD is socially isolating; not just for children with ASD but also for their families. In addition, mothers often worried about their ability to be the sole provider for their child as their child aged. As such, external joys arose for mothers when their child and they themselves developed bonds with others, in some instances, taking some of the pressure of being the primary caregiver off of them. Debra, for instance, experienced joy in watching her child “develop emotional connections with other people...[where he] seemed to value these other people in his life”. This arose in

light of not knowing “how much he would only just rely on me [as he aged]”. She went on to explain how it “took some of the pressure [of too many demands] off me; I didn’t feel like I needed to be everything to him, there are other people who could carry the load and that’s part of being a single parent too is having to do it all yourself.”

Also, despite the stressors associated with living in rural settings (described above), Meg expressed a joyous side to living in such a setting. Meg’s child developed bonds with others as a result of the community where they resided. Such a setting consisted of a “caring kind of culture” where there was and still is a “really good acceptance of Roy...people knew who he was, still know who he is, and are interested in how he’s doing”. Mary met an individual who “just turned his (her son’s) life around. I just can’t speak enough of this woman”. On a similar note, Sarah “met a lot of the wonderful people that came into our lives because of him, like you just meet a different cross of people, you really do...You meet a lot of stellar people and actually, one of the [teachers assistant’s] that was in his class that did after school care with him...she’s my best friend now”.

Thus far, examples of the stressors and joys, and outcomes experienced prior to placement have been discussed separately. However, joys and stressors can co-occur. A discussion of co-occurrences follows as it provides insights into some joys of caregiving and on a relatively new aspect of the stress-coping process (Folkman, 1997).

Joys Co-occurring with Stressors:

They always say whenever there’s a bad event, there is always something good to come out of it...Anne

In Folkman’s (1997) research on caregiving for men with HIV/AIDS, she discusses how positive states can co-occur with negative states. She found that in addition to experiencing high levels of distress, people also experienced co-occurring positive psychological states while caregiving and during bereavement (Folkman and Moskowitz, 2004; Folkman, 1997). The experience of mothers in this study supports this development in the stress-coping process; they discussed how negative outcomes and joyous outcomes derived from stressors sometimes co-occur. In other words, some stressors led to a co-occurrence of positive and negative outcomes, showing that stressors and their outcomes

need not be solely negative. Mothers mentioned co-occurrences in a number of situations, including: the receipt of a diagnosis, being employed outside of the home, and receiving social support. In addition, one mother described how a co-occurrence resulted from her child not being able to sleep.

Some mothers described the receipt of a diagnosis as a double-edged sword with a negative outcome of finding out that your child has a life-long disability and the joy of knowing what was wrong with their child. Debra explained:

Well there is part of the grief, 'cause even though I knew, to actually have it confirmed is a double edged thing; you're happy but on the other hand, it would be lovely if somebody said, 'oh no, it's just this', and they sprinkle pixie dust and your kid's normal. So, it was hard finally accepting that, you're looking at a life where I can't rely on [my child] taking care of me when I'm old...I'm always going to have to take care of him. He's never going to be independent.

Other co-occurrences were evident in mothers being employed outside of the home. Tammy discussed her employment:

Well I worked full time since my son was two. It might have even been before he was two...I've been there for quite a while. [Work has] been challenging partly because there's times where I'd rather have a break from work but because I'm the only wage earner...On the flip side, I have a pretty supportive work environment and...It's a mental break and I'd say at times even though my work place is quite chaotic, it can be less chaotic than home was or dealing with our son. I think it's good to have an identity outside of the home and outside of caregiving.

Mary, a teacher, expressed similar sentiments:

But I have needed to work and so it was good to have an adult professional life...but the other side of it is that I would come home tired. You deal with teenagers, you teach teenagers yourself, and you come home worn out...When I came home, it would be time to cook dinner and look after Sam, so it was mixed.

As reported above, social support has the potential to be a stressor for mothers. In addition, some mothers described the support they received as having a dual positive and negative impact. For example, the support given to Shelly by her family was described as "kind of a blessing and a curse". On one hand her family gave her support that "intrusive a bit", on the other hand, her mother was "very supportive...She was always there if I needed to call somebody." Formal supports that are intended to be supportive and beneficial to parents also have the potential to act as a stressor. When Jess sent her child

to respite, she explained how it was “harder on me, mentally, leaving her there (at respite), but physically I got a night’s sleep”.

The two mothers who implemented early intervention programs for their child with ASD both described negative outcomes associated with running this type of formal service because of the added demands placed on them. Debra talked about the logistical aspect of setting up and running an early intervention program for her child as a stressor. It was a “big thing to bite off and do...” Similarly, Lisa explained how implementing a program to toilet train her child as being “really all consuming...it took a lot of work... it was just a constant barrage of people”. However, Lisa also said, “a lot of times it was a help because they [the staff] could [look after her child with ASD]. Sometimes they would come and do therapy with him and it would be like an hour break, which was great.”

Lastly, a lack of sleep was described by Sarah as a negative stressor outcome resulting from the stressor of her child not being able to sleep. Sarah had to “go play in the park like at two o’clock in the morning” when her child could not sleep, which resulted in her thinking that she “was going to die [from lack of sleep]”. However, Sarah experienced a co-occurrence of joy from this event where she “didn’t [always] mind him being up in the middle of the night ...In a way, that kind of was a close time for the two of us”.

By providing a glance into the other side of caregiving, more is learned about these parents’ experiences and the impact of joys on them, in addition to events that cultivated joys. While it is important to examine both sides of caregiving, it is important to reemphasize that the joys presented above were few and far between, suggesting that the more stressful aspects of caregiving dominated parents’ experiences. Parents thus needed to cope with these demands. We now examine how parents coped with the demands of caregiving.

Part 3 – Parental coping prior to placement:

Coping refers to the ways individuals manage events that they perceive as stressful. In this study, the term parental coping is used to refer to the strategies or resources, either cognitive, behavioural, or social supports, that people use in order to

cope with the demands of caregiving. All mothers described coping as a significant part of their experience, which allowed them to continue in their caregiving role. Mothers talked about three primary ways of coping with the demands of caregiving: distancing themselves from the caregiving role or specific stressors derived from the caregiving role, seeking support, and tapping into their inner resources. It is important to note that parents did not use only one strategy or resource; all parents used a combination of coping resources and strategies.

All mothers distanced themselves from their caregiving role. One way parents did this was by accessing formal respite services directed at them. This type of service allowed mothers to leave their child with professional caregivers for a certain amount of time. When mothers were able to do this and the services were viewed as a break, it allowed mothers to “recharge” physically and mentally, away from their role of caregiver. Meg described the benefit of receiving respite as making “the difference between being able to carry on and not being able to”. She also mentioned how respite was good for her child with ASD as well: “I think for Roy [her child with ASD], it also made a big difference too, because there’s somebody fresh coming in...” Mary explained how respite provided her with a break and allowed her to rejuvenate “and [be] ready to take up the traces again. ‘Cause you love your child but you feel, it’s like a rope that’s getting frayed, if it isn’t re-worked, it’s going to snap”.

Respite need not be received from a formal service aimed specifically at the mother. In some instances, formal supports directed at their child with ASD also acted as a form of respite for mothers. Lisa, for instance, described the time when her child was at school as a break; “it was great. The first time he went to playschool, I gained five pounds in about two weeks ‘cause I wasn’t running; I wasn’t making these miraculous saves”. Lisa went on to explain the impact of receiving a break; “I could enjoy [my child with ASD] a lot more when he came home. You know, I had a chance to gain some energy back...all I needed was this little time to have some rest and regroup”.

Mothers also distanced themselves from their caregiving role through employment outside of the home. Among these mothers, there is a distinction made between employment outside of the home and working from home because the one mother who worked from home described work and caregiving as “all the same” (Meg)

where she was not able to get away from her role as caregiver. Jess and Sarah both explained how employment outside of the home provided them with a “breath of fresh air” away from their caregiving role, physically and mentally, allowing them to do things for themselves. Jess explained how work provided her with a role separate from that of caregiving. Employment affected Jess when she came home to caregive; it “gave me a sense of satisfaction, that now I can go again [caregive] but then I get to go to work again...It kept me going”. For Sara, work was “a blessing because at least it kept me sane”. Similar to employment, other mothers noted how doing things for themselves, such as exercising (Anne) and doing “things that were important to us” (Meg), helped them cope. For Anne, exercise gave her “more energy...allowed me to think...definitely a mental and physical health break and [it] really gives you enough energy to cope with the rest of the day”.

Some parents limited or modified their outings in order to distance themselves from the stressors associated with their child’s behaviours and the social stigmas they experienced. Jess explained:

I wouldn’t even take [my daughter with ASD] out into public anymore because an hour at Safeway would be an eight-hour job. It was awful, she’d be knocking stuff off the shelves, she’d be screaming her head off, I’d have run-ins with people in the grocery store saying, ‘what’s wrong with your kid?’ ... ‘cause people always thought the wrong thing, (whisper) ‘oh she must have been on drugs’ or, you know stuff like that, when they didn’t have a clue what they were talking about.

This adjustment might be considered a negative outcome. However, in the context of Jess’s experience, she described limiting her outings as a problem-focused coping strategy.

In order to cope with the demands of caregiving, parents also sought support from family and friends, and from seeking information. Informal supports assisted mothers in caregiving for their child with ASD. For instance, Shelly’s parents provided her with “a combination of emotional support plus helping us” with the care of her child with ASD. For Jess, informal supports from her mother provided her with an “extra hour of sleep”. Parents also coped by seeking information, mainly through reading books about ASD to help them understand what was wrong with their child. As Anne put it:

I’d go to the library and I’d go to the bookstore; I’ve got a whole library of books...When they labeled him attention deficit – I’ve got all of the books on

attention deficit. When they labeled [him as] high functioning autistic, then I got all those books. So I just wanted knowledge. I just wanted to know, because when you got knowledge, then you kind of know, you can plan a roadmap to see where we're kind of going here.

Anne also coped by seeking support from a formal support group. She described her experience with the group as “cathartic” because she was able to express her feelings to others who were in similar situations as her, as well as gain additional information based on the experiences of other mothers. Going to the support group also allowed Anne to “get out of the house” and thus provided her a break away from her caregiving role.

Some mothers coped by tapping into their inner resources or getting “it” from within, where “we just keep on going no matter what” (Sarah). Shelly, for instance, was forced “to tap into [her] own inner resources” in order to deal with the demands of caregiving. Others, such as Meg, expressed a “shift in consciousness” as a way of coping with her child’s problematic behaviours and sensitivity to certain stimulus. Jess coped with the bad days by thinking positively and having hope; “when the days start getting really bad, you just look at [my child with ASD] and we always thought that something will happen, she’ll get better or something’s got to turn around... We just always kept on thinking, ‘oh something will happen. Something will happen. Somebody will come along’...”

To conclude this section, we now turn to a discussion of ongoing appraisal to illustrate the ongoing and unfolding nature of parents’ experiences. By ending with this part, my hope is to break away from the more static layout of this section.

Part 4 – Ongoing appraisal:

All people appraise their situation as life events unfold on an ongoing basis. Mothers in this study were no different. The concept of ongoing appraisal was developed in chapter II to gain a better understanding of caregivers’ lived-experiences and is used here to gain insight into how stressors and joys do not occur within a vacuum. This concept describes how caregivers’ lived-experiences do not occur independently; they interact on an ongoing basis. Past events/experiences interact with present and future events/experiences when a person ongoingly assesses their situations via their appraisal processes. This conceptualization attempts to allow for a greater understanding of the

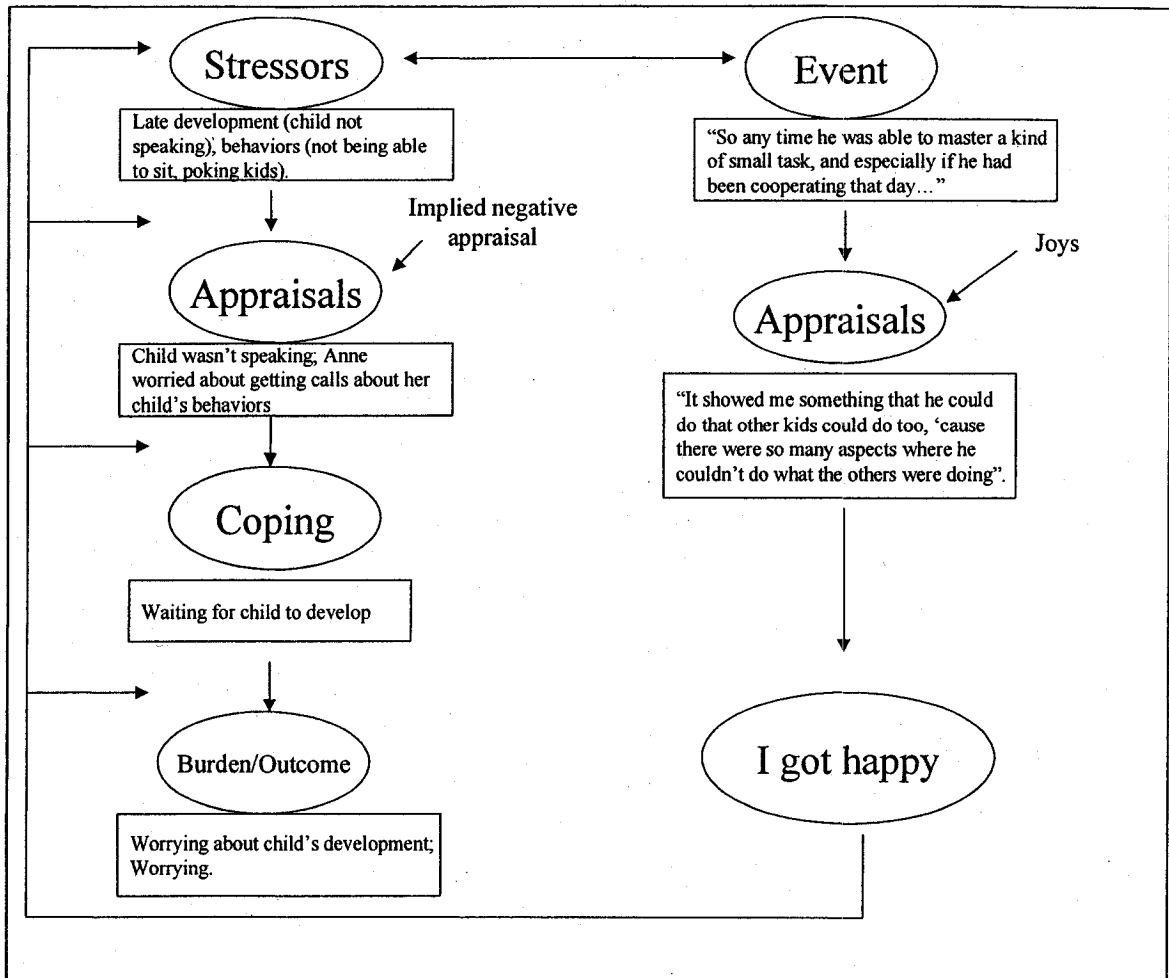
overall experience of caregiving. During the time prior to placement, parents provided insight into the concept of ongoing appraisal. In fact, throughout the interviews, mothers' discussed caregiving within a broader context of ongoing appraisal as life-events unfolded. I provide four examples of ongoing appraisal in the context of parents' experiences of joys and stressors.

The first example was described by Anne. During the earlier years of her child's development, her description of some pockets of joys exemplifies a process of ongoing appraisal during times devoid of negative behaviours.

I guess that [these situations] showed me normalcy. It showed me something that he could do that the other kids could do too, because there were so many aspects where he couldn't do what the others were doing...It's almost like breathing a sigh of relief, "oh good", you know we're kind of on the right track here because we knew he was progressing slower than the other kids, but as long as he was progressing.

By referring back to past experiences where she was worried about the development of her child, Anne, through a process of ongoing appraisal, experienced joy from her child developing in light of her worries about her son's lack of development. For example, in the past, her son would not or could not speak, he could not sit at his desk for five minutes, and he would poke the person sitting next to him during "circle" time. Anne refers to past experiences, and appraises the current situation of watching her son make developmental milestones and show good behavior as joyous "cause up until then he was very, very quiet and very shy and didn't want to try...he wasn't a child who could sit in his desk, he was all over the room..." This process is depicted in Figure 4.1.

Figure 4.1 - Ongoing appraisal- a joyous experience:



In Figure 4.1, Anne's child's late development (left side of the Figure) and the outcome of worrying about how her child would progress are past experiences that contribute to her present and future appraisal process, leading to the joy of seeing her child progress (right side of the Figure).

Lisa gave another example when she spoke about her child's development leading to hope. This process depicts ongoing appraisal, where past stressors (worrying about her child's future and not knowing how her child would develop) and joys (her child's accomplishment of being toilet trained) affected present and future appraisal processes. She explained how the joy of her child developing interacted with past stressors and how it interacted with past, present, and future appraisal processes. She described how being toilet trained made her son more "socially acceptable", providing Lisa with "a little bit of

hope” about her child’s future ability to further develop based on past development; “if you can do that, why can’t you do other things?” The hope resulting from her child being toilet trained also interacted with past appraisals of her child’s future, so that she now appraised how being toilet trained “really improved the outlook for his future. It improved the chances of him finding a spot in our home...” Both instances above describe how ongoing appraisal contributed to the experience of joys for these mothers. For instance, Anne and Lisa experienced joys from their child developing in light of the stressors of not knowing.

In contrast to the previous two examples, mothers also explained how the ongoing appraisal of situations led to more negative outcomes, such as the limiting of activities, which sometimes led to social isolation. Meg and Anne both described how a process of ongoing appraisal of past situations impacted their appraisal of present situations. Both experiences led to them limiting or modifying their outings with their child. For example, as her child aged, Meg had an experience with her child that “colored” every experience after it.

We used to have a cabin on the other side of the lake and we used to take him over there sometimes. We had a big, big swing set up between two trees, a rope swing, he used to love that thing, and so I was coming back from there (driving) and he got mad at me and I had no idea why...Then he started hitting me ... He started hitting me and I don’t know what he’s hitting me for, and I said ‘Roy [her son with ASD] cut that out’, and he just kept hitting me. So I parked, got him out and had him sit on the side of the road for timeout for a while and put him in the backseat and he started hitting me again; I was like blocking him and trying to get him to quit hitting me and I got out...had him sit on the side of the road again, he sits there...it took me a long time to get home and I had no way of calling Mark ...I didn’t know what to do... I could not get him to quit hitting me, I didn’t know why he was hitting me...I had to ask him ‘what is it? What do you want?’ and he wouldn’t tell me and then he looked fine and he’d say ‘no’ and then I’d drive and then he started hitting me again ... he was hitting me really hard and I was getting bruises and I was trying to hold him back and it scared me...It sort of has colored every trip, and that was a couple of years ago, but its colored all my trips, like I’m less committed I think to driving places with him than I used to be because I’m afraid I’ll get killed.

Anne described a similar experience (depicted in Figure 4.2):

I used to have to have him in the front seat because if I put him in the back he’d be all over his brother and sister so, I’d keep him up in the front; that was ‘till he start to [get more aggressive]...So then it limited my outings because...he and I

would [only] go out or I would take the other kids out if I could leave him home with his dad or something...I wouldn't have all three of them, the three younger ones with me. So, yeah that caused a lot of stress... Shocked, resentful...I would often have to cut short my trips and I wouldn't accomplish what I wanted to do. So it forced me to simplify outings you know, we would just go and do one thing and if it didn't work out ... we'd go home. And then thinking 'well that was a waste of money, a waste of time and why did I bother doing that?'

Exemplifying ongoing appraisal, Meg and Anne explained that an experience with their child in the past impacted their present and future appraisal processes – they always questioned “should we do this or shouldn't we? Is it worth it or not”? (Anne). This appraisal led to an outcome of limiting or modifying their outings.

Figure 4.2 - Ongoing appraisal – a stressful experience:

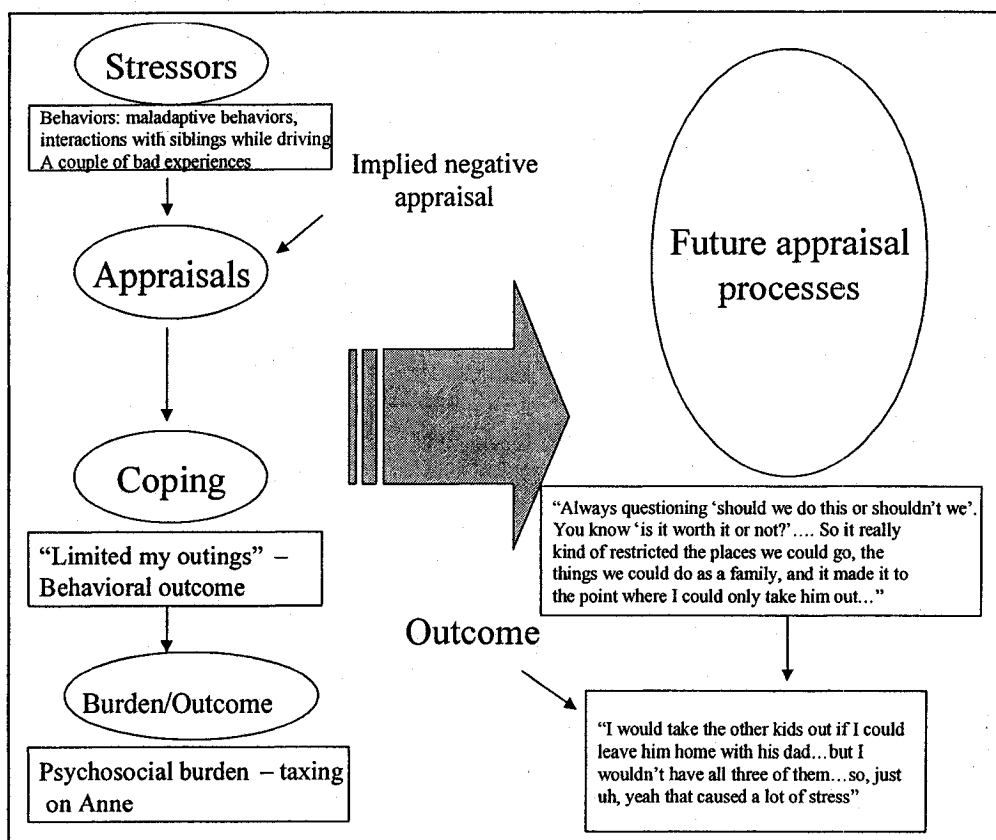


Figure 4.2 depicts ongoing appraisal where past events associated with the stressor of Anne's child's behaviours (left side of the Figure) had an impact on her present and future appraisal processes (right side of the Figure) whereby Anne would no longer take her child out alone.

Conclusion:

This section examined parents' lived-experiences prior to placement, with a focus on the stressors, joys, and how they coped with the demands of caregiving. As their child aged, however, parents described a transition from being able to cope to an appraised inability to cope. The section that follows explores this time period and the factors that led to the subsequent decision to place their child outside of the home.

Section 2 –Mothers' Inability To Go On and Their Decision to Place:

After discussing the early years of their child's development, mothers were asked to talk about the time leading up to their child leaving the home. Interview questions asked, "Can you talk about what led up to your child leaving home? What led up to placement? How did that impact you? Was there anything joyous during this time? How did you cope during this time?" Parents discussed two distinct periods: a period leading up to the decision to place resulting from their inability to cope and the period following this decision leading to the child actually leaving home. This section examines the former period and the section that follows examines the latter period.

All mothers described the time prior to placement as a transition from an appraised ability to cope (as seen in section 1) to an appraised inability to cope, which led to their decision to place. Parents talked about many factors associated with this transition, including an increase in severity of stressors and negative outcomes, lack of joys, and a lack of coping strategies and resources. Parents talked about similar stressors as described in section 1, the difference being an increase in severity and intensity, leading to more severe negative outcomes (Part 1). In parts 2 and 3, I discuss parents' lack of joys and how they tried to cope but were unable to do so. I end this section with a brief discussion of parents' process of ongoing appraisal. Unique to this time, all mothers reappraised their situations to an inability to cope and a decision to place.

Part 1 – Increased Severity of Stressors:

...And then it happened very, very quickly. I guess when she was about twelve or eleven...and her behaviour just became really wild, she became quite depressed, she kept having anxiety attacks and when she had those anxiety attacks, she was just a loose cannon, look out because she was ahh. I mean she attacked us, she attacked (her sister), she attacked my mom, she attacked...she wouldn't let my

parents come over anymore. Well, I mean they could but it would be utter hell. She just became so violent that we just couldn't manage. (Shelly)

The change in the mothers' lives was pungently illustrated in our conversations. Mothers talked about an increase in severity and intensity of the stressors. More specifically, they identified their child's autistic traits and multifaceted maladaptive behaviours as harder to deal with as time went on. This increase in severity of stressors led to more severe reactions of stress, in the form of increased severity of negative outcomes.

For example, due to her child getting bigger and stronger, Anne explained how his behaviours started "getting more intense" (Anne) and therefore, more difficult to deal with. Tammy expressed a similar situation:

...His behaviours went from just being the typical autism behaviours that we were able to cope with to being very extreme and including self abuse and physical violence towards ourselves and caregivers, school mates, all that sort of stuff, which is what led to placement...The school would be frequently sending him home because they weren't able to cope with him so...It quickly spiraled from manageable behaviours to completely out of control.

In addition, and as a possible result of the increase in severity of stressors deriving from the caregiving role, parents talked about how this led to an increased severity of external stressors deriving from outside of this role, specifically for mothers who were, or felt like, lone parents. For instance, Tammy's partner had a physical disability. As her child became bigger and more aggressive, Tammy explained how "it became more difficult for him [her husband] the larger our son got". Her partner's disability "made it more dangerous and challenging to caregive from his dad's perspective". She went on to explain how the stressors associated with being a lone parent increased; "as [my child with ASD] grew and [his dad] was able to do less because of his back, that was definitely stressful because you kind of take on, absorb the role of caregiving that he was doing".

Increased Severity of Negative Outcomes:

As the severity of stressors increased, the severity of associated negative outcomes increased as well. Mothers' descriptions of negative outcomes were more poignant and desperate. They explained how the demands of caregiving were taking an

increased toll on them and their families. It is important to note that the increase in severity of stressors probably did not solely lead to an increase in severity of negative outcomes. It is more likely that experiencing a lack of joys (part 2) and a lack of coping strategies and resources (part 3) in combination with the increase in severity of stressors contributed to this escalating severity of negative outcomes which culminated in parents appraising their inability to go on as caregivers. Because it is difficult, if not impossible, to empirically separate the outcomes of events from the contexts in which they occur, I try to portray the complexity of parents' lived-experiences in part 4.

During this time, parents primarily discussed negative psychosocial outcomes. For example, previously parents talked about having symptoms of depression, resentment and anger, and being constantly anxious and on guard. At this time, talk shifted to feeling as if they were going "completely insane" (Sarah), having suicidal thoughts, or being "ready to go off the deep end...I am literally ready to pack her in because I didn't know what to do anymore...I didn't know, I just didn't have any energy left in me" (Jess). Jess described how she "walked around in a fog all the time. I didn't know if I was coming or going half the time. I was so tired I couldn't even remember where I put something". Sarah explained a situation of complete desperation where, because of the demands of caregiving, she thought that she was not only "going to kill myself, I was going to kill [her child with ASD]. That was the truth of the matter". Other mothers, like Meg, were "exhausted... there's only a certain number of years that a person can live like that, from crisis to crisis and always trying to figure out what to do with the next obsession and how to manage it...I just couldn't manage it anymore". Lisa described a "descent into craziness" where "I just felt not in control of myself, I felt that I couldn't cope with any other, even little things".

All mothers characterized this time as a time their families were "in crisis". Lisa explained:

You know you're just slogging along now and everything started to become too much. Everything became [too much]. It's like when someone's body goes into shock, your blood leaves your extremities and focuses on the core, and that's like when a family goes into a crisis, you stop focusing on the extremities and you go into the core, that means like external things...any kind of recreation, you start cutting off everything that's not completely critical and you focus on only the

critical things. And that's what it was like. I focused only on what was important when the stresses got to be too much.

On a similar note, mothers talked about an increase in concerns for their own safety, the safety of their family, and the safety of their child with ASD. For example, Anne's child "was too large to restrain...it was getting to the point where we were afraid, we were really afraid someone was going to get hurt" (Anne).

Parents also discussed their household transforming into chaos. Anne described a home in chaos, where she was "down in the big black hole":

I phoned the social worker in tears and just described how things had been going at home, which at that time had been very, very bad; that we were all just in chaos, I mean everybody was upset with everybody else and Tom's behaviour was getting worse and something else had been broken.

Along similar lines, but more of a behavioural outcome, Lisa mentioned a transformation of her household into an "Alcatraz fortress so that no one can get in, no one can get out, nothing bad can happen but you do it like one door knob at a time".

In addition to the increase in severity of stressors and negative outcomes, parents also described a lack of joys. While a lack of joys might be considered a negative psychosocial outcome, I separate this aspect of caregivers' experiences because it is unique compared to the time before it.

Part 2 – The Joys of Caregiving:

When the stresses got to be too much, the joy of everything started to disappear.
(Lisa)

Parents did not describe any joys or positive outcomes associated with this time. On the contrary, some parents described the time leading up to their appraised inability to cope as a time devoid of joys. Sarah explained: "I don't remember a lot of it being positive because...his behaviours were bad during that time. I tend to only remember that he was really, really rotten during that period". Shelly expressed similar sentiments, saying "to be honest, there wasn't a lot of anything joyous during the year leading up to May leaving". This finding supports Cummins (2001) who suggests that when parents are unable to describe any joys of caregiving the burden is probably inoperable. Mothers

tried to cope with this time but did not have the resources and strategies available to do so, as depicted next.

Part 3 – Parental Coping:

When I was really, really down and everything we tried wasn't working, it can be very, very frustrating and very exhausting...and then you feel very guilty because that is not how you're suppose to feel as a parent. (Anne)

As illustrated above, parents talked about an increase in the severity of stressors and negative outcomes, in addition to experiencing a lack of joys. In an attempt to cope with the demands, mothers employed similar coping strategies and resources that had helped them cope before. However, they were unsuccessful/ineffective. In describing why they were unable to cope, mothers talked about a shift in the availability and effectiveness of coping strategies and resources. They described how before this time, formal and informal supports and personal coping strategies were available and working to help them, whereas now, these strategies and resources were taken away, were simply unavailable, or were not working. The fact that mothers could not cope led to additional consequences; they changed their thinking about their ability to raise their child with ASD and what was best for them and their family.

Mothers lost services and supports either due to the age of their child or as a direct result of an increase in their child's behaviours. Lisa's child, for instance, lost early intervention services due to his age. These services proved to be essential for both Lisa and her child's well-being. When they were taken away, Lisa explained the impact: not only did her child's "behaviours started to deteriorate, once he was out of the environment where people knew how to deal with him...", the stress of everything "increased" for her. She went on to explain how "I would have done anything for a break". Mothers also lost services and supports due to an increase in severity of their child's behaviours. Shelly, Anne, Meg, and Mary all "started losing the respite [services]" (Shelly). As a result of losing respite, they did not receive any breaks from their caregiving role. Without respite, one mother described how she was "literally trapped in [her] house with a dictator..." (Shelly).

For some, services were simply unavailable as the demands of caregiving increased. Jess and Tammy talked about being "lost within a system" of formal services

(Jess) where no help was available to facilitate coping. Jess did not receive any breaks from caregiving. Tammy described a similar situation where she and her child were unable to access services “because they don’t exist until [the child is] fourteen in town”. Because of this gap, Tammy “basically suffered at home with this cycle of abuse and violence...” Similar to Jess and Tammy, Sarah could not access any formal supports. She explained, “no matter where I turned I couldn’t get help”. As a result, “...I was never getting a rest. My husband would take him and stuff like that but it’s not the same. When do you have time with your husband?”

Mothers’ personal coping strategies that had worked before were also removed or were no longer effective; as one mother said, “...we had exhausted all the resources” (Anne). For example, as Meg’s son aged, she described how he “started going to bed at nine o’clock instead of 8 o’clock”. Referring back to the earlier years of her child’s development, Meg had relied on the time after her child went to bed until she went to bed (an hour), to recharge. As her child aged and started to go to bed later, this time to cope was taken away. As a result, Meg “started to go downhill just in terms of being able to cope and I think it was just never having a chance to think”. She did not realize how much she had relied on this hour until it disappeared. During this period, Meg was “physically in pain most of the time...and just really couldn’t seem to be able to cope...I’m crying in pain all the time, I can’t even go to the store half the time, like I’m falling apart”.

Before this time, parents were able to manage. At this time, parents described surviving, “...getting by, by the skin of my teeth” (Debra). Anne explained, “when I was at my worst, when I was really down and everything we tried wasn’t working ... so then you kind of go into this robotic mode where you do everything you’re supposed to do as a parent but there’s no real feelings that go along with it”. In this survival mode, parents reappraised their situation, which led to the conclusion that they were no longer able to go on caregiving for their child. This reappraisal led to their decision to place their child with ASD outside of the home.

Part 4 –Reappraisal and Parents’ Decision to Place:

I started exploring putting him into care because it was just too much going on; I was mentally, physically, spiritually starting to breakdown and saw that where we were headed wasn't necessarily good for anyone in the family. (Debra)

Mothers’ experiences of the stressors, lack of joys, parental coping, and negative outcomes discussed above all contributed to their inability to cope; these factors did not occur in isolation from each other. As previously described in section 1, ongoing appraisal illustrates how individuals assess their situation as life-events unfold. Unique to this time period, and based on their ongoing appraisal of their situation, mothers described a process of reappraisal, through which they concluded that they “just couldn’t manage [to caregive] anymore” (Meg) and that things “could only get worse unless we move forward with this (placement)” (Debra). This suggests that ongoing appraisal leads to intermittent reappraisal of caregivers’ situations, perhaps during times of severe distress.

For example, Anne went through a process of reappraising her present situation based on past situations. This in turn impacted what she thought the future would be like. Her appraised inability to cope, which led to the decision to place, was the outcome of a reappraisal process by which Anne had a bleak outlook of her situation; “it was to the point where someone was going to have to get hurt in order for things to get better and I didn’t want to wait that long. I didn’t want to wait for somebody to get carried off on a stretcher because that’s how it was looking like it was going to happen.” She went on, “we could see that we were just going to continue in the same pattern that we always had, that Tom was going to kind of rule the household...it was happening and it was just going to continue, we were never going to get any better...” In the end, reappraisal resulted in the conclusion that “we needed a break”, which led to her child being placed. In order to cope with the inability to cope, placement was the only option.

Another example was given by Shelly who talked about losing respite, in addition to her child’s increased behaviours, which acted as “kind of the catalyst” for her to place her child. With the loss of respite services, she reappraised her situation and concluded, “I couldn’t have functioned without [respite]...we just couldn’t manage”. She went on to explain how she “just knew that this wasn’t healthy...it was becoming a welfare

concern". She reappraised her situation as being unable to manage the demands of caregiving, which contributed to her decision to place.

Conclusion:

The findings suggest that placement arose as the only option in order to survive; it was a way to cope with their inability to cope. As one mother explained, "I don't actually feel like I had a decision...I really felt like there's no option here" (Meg). This section contributes to an understanding of some factors associated with the decision to place a child with ASD, which informs an understudied aspect of parents' lived-experiences. Section 3 is a description of the time between a parent's decision to place and the child leaving the home, which was often a lengthy process.

Section 3 – Leading Up to Placement, After the Decision:

In section 2, I described parents' experiences leading up to their appraised inability to cope and their subsequent decision to place their child with ASD. Once parents made the decision to place, they entered into an institutional placement process and waited for a placement position to arise. Wait times ranged from a few weeks to many months. The term "placement process" is used here to refer to the time after parents made their decision to place and were entered into a textually mediated process. It is conceivable that this process began even before parents decided to place their child. For instance, a social worker might have started to plan for placement before the mother recognized her need for placement. To gain a better understanding of their experiences, I asked mothers to talk about this time. Similar to the time before it, they continued to talk about their inability to cope. They also discussed stressors, joys, and coping strategies and resources unique to this time. While the placement process differed from mother to mother, the experiences they described were indicative of other textually mediated processes and relations that coordinated and organized mothers' lived-experiences prior to placement (such as the diagnostic process of ASD) (Corman, 2005, b). These relations or processes are outside the scope of this study and warrant further investigation.

Part 1 of this section focuses on three unique stressors related to the time following the decision to place. Mothers also talked about how these stressors led to

negative outcomes. Part 2 focuses on the joys during this time. As already mentioned, parents did not express any joys during the time leading up to their appraised inability to cope. At this point in time, however, parents' ongoing appraisal of their situation led to the prospect of placement being a joy for some mothers; as they saw that a break was on the horizon. Part 3 discusses how parents coped during this time.

Part 1 – Stressors After the Decision to Place:

Mothers talked about how the actual decision to place and the realization that their child would no longer be living at home both acted as stressors. In addition, and corollary to the decision to place, parents expressed logistical stressors that they encountered during this time. Mothers also talked about a stigma associated with placing a child in out-of-home care. These three stressors are described below. Due to the difficulty in empirically separating stressors from their outcomes, the stressors discussed below incorporate their outcomes.

Although mothers were unable to cope and had “no option” other than placing their child, all parents struggled and “wrestled” with their decision to place once it was made. They all experienced negative psychosocial outcomes during this time, such as feeling guilty or like failures as mothers for not being able to caregive for their child. For instance, Anne “wrestled with that decision because even though things were really bad at home, the thought of sending him somewhere else, I felt like a horrible parent, [like] we’re abandoning our child [because] we’re sending him somewhere else to live”. Debra experienced “a fairly agonizing process of coming to terms with [the decision to place]”, not just with the “logistics” of actually placing her child but coming to terms with her appraised inability to cope and guilt that resulted. She explained, “I couldn’t help but feel that as a mother, somehow I was failing; that I wasn’t doing enough [and] that I couldn’t be what he needed”. Similarly, Mary mentioned coming to terms with the prospect of her child being placed. She talked about how even the “idea that he was no longer going to be living with me” was hard to deal with. She also felt as if the bond between her and her child was “going to be broken and never be the same”. Lastly, Lisa described “feelings of finality. That change was coming ... you know you’re thinking ‘oh, one of my kids is leaving our house and going to be placed’, and you feel like a failure”.

Mothers also talked about the logistics or practical aspects that have to be considered when placing a child. These logistics were corollary to their decision to place. For instance, Mary found the process of figuring out where her child was going to be placed as difficult. She described how it was stressful to receive “different calls from the social worker about different (foster care) families”. Anne was concerned about how they were “going to even get him there [placement]” due to her son’s behaviours and unwillingness to initially go. She went on to explain, “I was afraid he’d run away before we got him there”. Unique to Anne’s experience, and possibly due to her child’s level of functioning (relatively high), she found it difficult to explain her decision about placement to her child with ASD. She explained:

How do we explain [it to him]...that it’s not that we didn’t love him but that we wanted to help him, which is basically what we said. It ended up my husband actually was the one who talked, ‘cause I couldn’t, I knew I was going to break down – I knew I wouldn’t be able to do it. So I sat there and quietly broke down while my husband talked to my son and strangely enough my son listened and didn’t negatively react.

Mothers also talked about not knowing how ordinary tasks would be done once their child left home. For example, Debra was concerned about “birthday presents, birthday parties, holidays, who signs the permission slips for the field trips? Trips to the hospital?”

Parents also talked about felt stigma¹⁸ associated with placing a child outside the home. Felt stigma here refers to stigma experienced by mothers who feel shameful or express a fear of rejection relating to how others might view their parenting ability and decision to place. For Meg, there was a “huge social stigma to placing a child outside of your home”. She explained how this stressor was “externally imposed” upon her where “if you’re a good family with a child with a disability, you keep your kid at home and if you’re a bad family or dysfunctional or something’s wrong with you, then you let your kid go into care and you’re not a family anymore”. Because of this stigma, it made Meg’s decision to place and coming to terms with placement more difficult to deal with. She explained:

[Stigma] made the decision close to impossible. It put me in a situation where, I think of it as a near death experience... because of just refusing to be a bad

¹⁸ This stigma occurred in both sections 2 and 3. I mention it here because Meg and others discussed it in the context of waiting for their child to leave home, after their decision to place was made.

parent... 'Cause I think that if I wasn't a person of faith, I might have committed suicide and I'm surprised more people don't because that's a death of despair and hopelessness... If you haven't lived it it's hard to believe that it can happen to a regular person like me.

Similar to Meg, for Deb, this stigma increased "the anxiety level... It makes it harder". She went on to say how she worried about "what other people would think" once her child left home; "you worry that people judge you ...it's a minefield".

This part illustrated parents' experiences of stressors and negative outcomes during the time after their decision to place. Unlike the time before it, this time was not devoid of joys; however, they were limited. While the parents did not talk about similar joys as those described in section 1, they did express one unique joy during this time. This joy co-occurred with the stressors that were described above.

Part 2 – Joys of Caregiving After the Decision to Place:

Well, you're thinking 'one of my kids is leaving our house and going to be placed', and you feel like a failure. At the same time you're looking forward to having a change in a household that has sadly deteriorated... so you look forward to spending more time with the girls and being able to do things as a family and on the other hand you're sad 'cause he's leaving, on the other hand you're happy that he's leaving because you're exhausted and you just need that change. (Lisa)

Knowing that their child would soon be leaving the home, all mothers expressed feeling guilt and failure, as depicted in part 1 of this section. Simultaneously, parents also described a positive side of knowing that their child would soon be leaving the home. This joy emerged through a process of ongoing appraisal; knowing that their child would soon be leaving the home, mothers expressed a hope for the future and a return to a time that they felt would be normal.

Most parents described the time between their appraised inability to cope and their child leaving home as a time of hope for themselves and their family's future, knowing that placement was on the horizon. Anne explained how there were "possibilities in the future that we hadn't really thought about because we were in survival mode up until that point... you start thinking 'oh maybe we can do this, maybe we can do that. I'd like to do this. I'd like to do that'. For her, this was "an exciting time". She went on to explain how this was joyous because "there's something to look

forward too...yes you're still going to have difficulties day in, day out until that time comes along, but you know you only have a certain period of time to wait and then there's going to be a new situation occurring. So that was very positive".

The prospect of a return to "normality" was joyous for mothers, as it brought them hope for future possibilities. Parents still needed to cope with the demands unique to this time. The coping strategies and resources discussed below differ from other sections. Previously, parental coping targeted the direct demands of caregiving, at this time, coping targeted the stressors associated with the placement process. Parental coping was not aimed at mediating the direct demands of caregiving, perhaps because parents were unable to cope with these demands (section 2). What follows is how parents coped during the placement process.

Part 3 – Parental Coping After the Decision to Place:

...I had [support] from close family members and my friends...it was somebody to talk to. It takes away the feeling of isolation even though my friends have never been in this situation, they felt that I was making the right decision and I needed somebody to reinforce this decision". (Mary)

Mothers were asked to describe how they coped after their decision to place and leading up to their child leaving home. Similar to section 2, parents still described their inability to cope. However, they described how various strategies and resources helped them mediate the stressors and negative outcomes unique to this time. In other words, while parental coping mediated the effects of stressors associated with this time, parents were still surviving rather than coping. They were surviving, "which is why [their children] ended up in care". Meg explained how she was surviving by just hoping for a break and knowing that her child would soon be leaving the home. This allowed her to continue on caregiving.

Well by that time I was so wrecked that [placement] was a point of hope for me. It was like I'm just going to survive and then in another month, and then it kept getting pushed back, and another month, and another month, and another month... 'We'll have things in order and then you can move out and then I can get some sleep', and...I was sort of pinning all my hopes on getting some rest and recovering.

Parents accessed both formal and informal supports and came to terms with their situation through what can be considered emotion-focused coping; they used cognitive efforts to control and regulate their “emotional responses to the event” (Slavin et al., 1991: 158). Some mothers described a unique way of coping associated with the joyous prospect of their child leaving home.

Some parents accessed formal supports. Debra, for instance, spoke with people from the Autism Society and her social worker to help with the additional demands of this time. She talked about how the Autism Society was “supportive all around”. She also mentioned how her social worker was helpful because he “had some personal experience with putting a child into care, and that was really [helpful]... to see the man sitting across the desk from me and know that he has been there...” Jess accessed respite services to cope with her child and the estimated six-month wait between her appraised inability to cope, moving to Alberta, and to the time of her child actually leaving the home. Mothers also coped by accessing informal supports, which included support from family members and friends to help them to deal with challenges involved with placement. Mary’s family and friends, for instance, helped her cope with her decision to place by having “somebody to talk to” which “takes away the feeling of isolation...they felt that I was making the right decision and I needed somebody to reinforce this decision”.

Similar to coping by “getting it from within”, Meg went through a process of reconciliation, where she used cognitive efforts to come to terms with the stigma she struggled with. She described this as a “learning process”, where she had to recognize the social stigma “so that I could examine it”. Recognizing it made it possible for her to “finally kind of reconcile myself” to the decision to place. Debra went through a similar process where she came to the understanding that “I’m being the best mother to him by acknowledging that I can’t do it all and that...it takes a village to raise a child”.

Mothers described a unique way of coping during this time. The prospect of placement was joyous because mothers saw a return to normality in their near future (described in part 2 of this section). This joy additionally helped some mothers cope by acting as a mental respite. For example, Anne talked about how this joy “was just something positive to look forward to. And even if I was having a bad day with him, I could kind of go ‘yes but...don’t forget, he’s going to the Centre...Like the respite time,

like yes we're having a hard time today but don't forget, tomorrow is respite day." Exemplifying a process of ongoing appraisal, this joy of future hope helped Anne deal with the demands unique to this time.

Conclusion:

This section explored parents' experiences leading up to their child leaving the home. Mothers described unique stressors, joy, and coping strategies and resources during this time. This time culminated with the placement of their child with ASD. While most mothers anticipated a return to normality once placement became a reality, what happened was quite the opposite. An examination of mothers' lived-experiences after placement follows.

Section 4 – Mothers' Experiences After Placement:

Once mothers entered the placement process and a position for their child became available, their child eventually left home. Placement of these children did not mean that mothers stopped caregiving. To the contrary, all mothers described still taking an active part in their child's life, to this day. The purpose of this section is to gain a better understanding of mothers' experiences after their child left home.

When mothers were asked to talk about their experience after placement, they mentioned two distinct periods: a very stressful time immediately following placement, and a time when their life started to settle down and become more normal. In an attempt to more accurately reflect these experiences, I separate the time after placement into two sections. This section explores the time immediately following placement, a stressor-period. The subsequent section (section 5) explores the time after this stressor-period, what most mothers described as a time "after the dust settled". The current section is separated into three parts. Part 1 examines the stressors and negative outcomes mothers talked about after their child left home (their child leaving home as the stressor). This period varied in length from mother to mother; however, all mothers described it as a period devoid of joys and being unable to cope. As such, this time was similar to the time period portrayed in section 2. Differing from section 2, however, mothers' inability to cope was not because of stressors derived from the direct caregiving role and other stressors external to that role. To the contrary, mothers talked about how they were

unable to cope or experience joys because their child was no longer with them. In other words, though mothers experienced stress while their child was living at home, when their child left home, the stress was initially unbearable.

Part 1 – Stressor-period and Negative Outcomes Immediately Following Placement:

You feel like you failed as a parent. (Sarah)

Below, I report on the negative outcomes immediately following placement. I do not isolate this stressor from the outcomes because mothers implied their child being placed as the antecedent (stressor) and cause of these negative outcomes. Mothers discussed many negative outcomes, mainly psychosocial. They felt both empty and lost without their child and did not know how to function on their own. Also, mothers continued to describe guilt and anxiety. For instance, Shelly explained that when her child first left, “there was like a vacuum... Every day (emphasis) I’d wonder what she’s doing? I wondered how she’s feeling and I hope they know about this and I hope they know about that’...” She went on to talk about how this was “one of the lower moments of my life”. Tammy also talked about how “it’s a little bit of an empty nest syndrome going on” after placement. For others, their child leaving home felt “just like a death...like something’s ripped away from you, even though she was only ten minutes away, but you were there to watch her all night” (Jess).

Anne explained how she did not know what to do with herself or how to exist following placement.

I mean honestly I didn’t know what to do with myself the first few weeks he was gone because yes, I had my other kids and yes, there was issue around them and I was parenting them and that, but when your whole focus or like seventy-five percent of your focus is one child and he’s not there, it is just ooh. It was really hard, I mean I was in tears half the time...As autistic kids typically are like this, there were certain things he liked to do and he kind of got into his routines and one thing he liked to do was have me sit on his bed and talk to him just before he went to sleep and things like that, that no one was going to be doing that with him...I found myself thinking about, ‘oh’, like we used to give him medication every four hours so I’d be thinking, ‘oops, it’s time for another pill. Oops nope, we don’t even have Tom’. Like, even the whole medication thing, oh my gosh, we don’t have to give him medication for all this time.

Sarah similarly did not know what to do with herself. She explained how this impacted her behaviorally:

I would go shopping and I would start out very early in the morning and I would not come home until late at night because at that time they were letting him settle into the house and I wouldn't be able to see him. And I would just walk like for hours at a time, like twelve hours at a time 'cause I didn't know what to do with myself either.

Similar to other manifestations of stress throughout their experience, mothers continued to describe guilt, depression, and anxiety. Sarah explained:

I couldn't bear the thought of [her child] being away from me and yet I couldn't bear to be with him (laugh). There's a lot of things, I mean, there was a lot of guilt ... on that level I think we did a really good thing and I see like the positive things, but when you're doing this you feel like you're the worst parent in the world. For starters because you think oh I should be able to manage it but you can't really. It's very challenging...I'd like to be able to handle it but I can't.

She went on: "[it was] really depressing 'cause I felt really, really bad about the whole thing.

Lisa described a delayed reaction from all other mothers immediately following placement. She talked about a "honeymoon period" where she experienced a brief period of joy:

Ok the honeymoon period...taking the locks off the doors, taking all those doorknob covers off, that was really neat. It's kind of a blur. I remember going out with a group of women from our neighborhood and one of the woman was in there and she said to me, she said 'how's it going?'. I said 'it's great'. She goes, 'just be prepared for the honeymoon period to end, that it's going to come crashing down on you'. And I said, 'how dare you say that, I'm so happy, things are so good'...

As predicted by one of her friends in the quote above, two weeks after her child left home, the honeymoon period came "crashing down". Following the honeymoon period, Lisa described a stressor-period similar to that of other mothers immediately following placement:

And then two weeks later [after placement] I'm crying in the pediatricians office...I had no idea that it was this stressful for me 'cause it never even popped into my mind, and then I was sitting there talking to her [the pediatrician] and all of a sudden I'm bawling. And then the nurses are calling me and they're saying 'yeah, we've seen this before, and you'd probably be best off to get talking to someone who's in a similar circumstance', which I did.

Despite Lisa's "honeymoon period" immediately following placement, once the honeymoon period came crashing down, superseded by the stressor-period, she experienced similar negative psychosocial outcomes as discussed by the other mothers.

Lisa explained her experience of developing "severe anxiety over the next year":

[The anxiety] peaked at a year after he went into care and then it seemed to sort of subside...I really operate on adrenaline; I've got a lot of energy, like a goalie on a hockey team, I was constantly doing this and suddenly that was gone...Where do you put all that energy? So I think it was a real coming down process of family readjustment... Yeah, I was pretty anxious for that first year...so I mean we're together all the time; we're together twenty-four seven and Ian's gone...It was very odd, conflicting, anxiety ridden; even the girls were weird for a while.

In addition to the psychosocial outcomes mentioned above, Sarah described a physical outcome. She explained how the "stress" started to manifest itself in a really physical way, "something happened, all my muscles stiffened up and I couldn't walk. That was very frustrating because everything started to manifest itself physically. So I had a lot of illness..."¹⁹

Parents did not describe any specific joys during this time. Anne, for instance, explained how she "found it very, very stressful, very difficult when he was gone initially; I couldn't enjoy myself at all, I felt guilty for enjoying myself".

During this period, parents did not describe any unique coping strategies or resources. Anne explained: "when he was initially gone, my focus was gone and I just didn't know how to cope very well. So, it took me a few weeks, maybe a month, and then..." In fact, similar to the time leading up to a parents' appraised inability to cope (section 2), mothers were just surviving, perhaps waiting for, or hoping that things would subside. "It was really being in crisis...I don't know if I coped all that well actually 'cause, ultimately I took about a week and a half off work just 'cause I had burnt myself

¹⁹ Outside the scope of this study, other family members were also impacted during this time. For example, in addition to experiencing the stressor-period and negative outcomes immediately following placement, Lisa and Shelly both described how other members of their family were impacted in a negative way during this time. Shelly explained:

The whole family was just really rocked by it. I mean there was kind of a period of probably you know depression in here, around the house...What was funny is that when May left the house, the house became very quiet and we realized just how much space she had taken up, but even though some of that was intrusive, she was such a character and she brought a lot of life and laughter and energy...

out...Again it's just like you're hanging on by your fingernails" (Shelly). As such, all mothers "did not cope well". The exception was Lisa who, as described above, developed severe anxiety and "had to get medicated ..." in order to manage the stressor-period.

Conclusion:

For most mothers, this period settled after a certain amount of time passed, which will be the focus of the next section. However, for one mother it did not. After placement, Tammy seemed stuck and unable to exit this stressor-period. She talked about living in "a lot of fear of the unknown" after placement:

We've tried to live as normal a life as possible but it seems like our lives are really empty, like we have a lot of spare time so it's really hard to fill that...Like we don't see him on Saturday and Mondays so the weekends are very long...There's a lot of empty time, it's a little bit of an empty nest syndrome going on, so trying to fill our time with other things has been challenging but it's hard to go from being a caregiver all the time to having no one to care for.

A combination of factors contributed to this negative outcome for her, including more chronic stressors associated with the placement process (leading up to and after placement). For instance, she described how she felt "forced" into placing her child into a facility that "wasn't a suitable placement". She also described an "ongoing battle" with the caregivers at the placement facility to provide appropriate care for her child. She explained:

...[My child with ASD has] been there for a year. We've been trying to negotiate the implementation of his program, which still hasn't been done. That's extremely stressful because he requires that order in order to be able to function on a daily basis.

Despite all of her efforts, they "still haven't been able to implement any of that for him so he pretty much lives in chaos not knowing what comes next". Tammy compared her experience before and after placement:

Still as stressful in a different type of stress...I'd say it's as stressful if not more... at least when your child is home with you, you know that they're safe relatively speaking I guess. There's a lot of unknowns, we have our son in a place that we don't really trust. It really impacted our ability to sleep at night... (Mike: Really!) Oh yeah, significantly impacted...like [both me and my partner's] sleeping has been limited over the past year [since placement], living a lot of fear of the unknown; you don't know what your child's experiencing when you're not there to watch out for him.

Differing from Tammy's experience, all other mothers describe a transition following placement to a time after the dust settled. However, while this happened for most, the stressors of placement did not go away. In fact, after placement mothers described their child's placement as a chronic stressor that went into abeyance. For instance, Mary explained how the stressor and outcomes associated with this time are "...just there always...this doesn't go to a quiet place" (Mary). Another mother explained the stressor as being on the "backburner, like it's no longer taking up emotional energy, space, [and] time" (Shelly). Others described how the "grief part of it never goes away...it's just there and it doesn't go away, and it's a grief of loss, it's a loss of dreams, a kind of family we could have had and thought we were going to have" (Meg).

Section 5 – Mothers' Experiences "After the Dust Settled":

Following placement and the immediate stressor-period, most mothers transitioned to the time "after the dust [of placement] settled" (Shelly). Mary explained: "My feeling [is] that it's about six months before you even really begin to deal with the grief [after placement]...you just shut down". Likewise, for Shelly, "[her child's father], her sister and I were in mourning for about, you know particularly the first three months after May left, and probably it sort of began to ease at that point... [Now] I don't feel like I'm mourning..." This time differed considerably from the period before it. While mothers' roles changed drastically after placement, they were all still active in their child's life. As such, they still experienced a multitude of stressors that were similar to the years before and leading up to placement. In addition, while mothers talked about these times differently, their concerns after the dust settled were connected to the decision to place and the institutional care that was provided to their children. Distinct stressors emerged that were associated with the facility in which their child was placed. This stressor could be viewed as either a stressor derived directly from the caregiving role and/or external to it. For instance, the facility could have been viewed as a direct stressor for mothers because of their desire to caregive for their child. On the other hand, the facility is out of the control of parents and can be viewed as a secondary stressor corollary to their decision to place. Mothers also experienced a multitude of joys after their child left home. Differing from the joys previously mentioned, these joys were

longer and more permanent. Parents also described an ability to cope during this time compared to the inability to cope in the prior period.

This section is separated into three parts. Part 1 examines the stressors and negative outcomes mothers talked about during this time. Part 2 discusses the joys of caregiving and how they differed from previously. In part 3, I report on how parents coped.

Part 1 – Stressors and Negative Outcomes After the Dust Settled:

Stressors arising from the direct caregiving role, even though their child was placed, were similar to the time prior to placement. These stressors arose because mothers still spent a lot of time with their child and their child was generally a “challenging kind of person” (Meg). For instance, mothers talked about taking their child out, having them over to their house for the weekend, going on holidays with their child, visiting them at the placement facility, etc. In other words, even though their child was placed, their stressful behaviours did not disappear; ASD is a chronic condition. So, when mothers spent time with their child, it was sometimes stressful. However, these stressors and their outcomes were not nearly as severe or chronic compared to the time prior to placement, as the child was no longer living at home day in and day out, and the mothers had roles outside that of caregiving.

Mothers mainly talked about stressors associated with placement, as described in the previous section; the difference is that this time was not solely consumed by stressors and negative outcomes, devoid of any joys or the ability to cope. Mothers also talked about unique stressors after the dust settled. These stressors all arose from the formal support system, and included those arising from the facility in which their child was placed and other institutional stressors derived from the placement process. I focus on these stressors below. Similar to other sections, I try and separate the stressors from their outcomes; however, some of the stressors described below incorporate their outcomes.

As previously mentioned, social “support”, when appraised in a negative light, can be a stressor that can have a negative impact on mothers. Depending on how mothers viewed the facility in which their child was placed, the facility had the potential to act as a stressor. Some mothers described the facility as a stressor. Jess talked about how she

was suspicious about the quality of care her child was receiving from the facility in which her child was placed.

I thought my suspicions and complaints about the [facility] were me being picky or me thinking, 'oh well, you guys shouldn't be doing this and you shouldn't be doing that, blah, blah', but in my gut I knew something was wrong... This isn't all it's cracked up to be, you guys are supposed to be taking the stress off me, you're causing me more stress leaving my kid here (emphasis). Then I got a call from the school and they said, 'Jess, you need to come up here', and I thought 'oh my god'. I went up to the school and they started telling me that the kids had been coming to school [from the facility] not properly dressed, going out in minus ten with no mitts, no hats, no boots. They had lunches in the fridge that had come in the lunch kits with green bologna in stale bread. The kids had been coming with three days of dirty clothes still in their backpack that they had sent home before; no clean clothes... stuff wasn't right. And these were a lot of the things that I'd be complaining about previously... When I'd go up to [the facility] at night, and Kate was there by herself, there was nobody looking after her... That's when it was winter time and she was drooling and stuff then. Her t-shirt would be literally soaked, literally soaked (emphasis), and she'd have bare-feet on and I'd feel her feet and her feet were just frozen, her arms were freezing. And I'd go crazy. Like what are you people doing up here that my kid is sick because of this?... The personal care was awful. It was awful.

Even though their children were placed, the placement process was not over. For example, following placement, some parents expressed concerns about their child "getting moved around too much" (Meg), as a result of institutional "hoops" that had to be jumped through as part of the placement process. In addition due to certain institutional policies for placing a child in British Columbia, Meg's child first had to be placed in foster care, which had to fail before her child would be placed in a group home (Meg's preference). Meg explained how she "...didn't think it [the foster care placement] would work..." She viewed the initial placement as "a hoop that had to be gone through, or a stupid hoop, a dumb idea, it wasn't going to work, so that we could say we did it and get him in a group home... So it was a very long, drawn out ordeal to try to get Roy where he really needed to be". Even after her child was placed into a group home, Meg described how he was still moved around:

In the beginning, in the group home, they had a house... it was stressful a bit too, he moved... it was meant to be like a temporary thing; get things set up and then they would find a real house, and it wasn't in a very good place, it was on a busy street and I was worried because we had like all these sort of things set up for Roy in terms of his pictures and having hooks; we had to put things and all his

routines, and they didn't seem to have any of that ordered, and they had to train all their staff and then (sigh) two months later they moved him to this new place...

Sarah also expressed concern about the prospect of her child being moved around. She said, "the Ministry [of Children and Family Development, British Columbia] is not that understanding of kids and they don't realize...[that] it's not ok for an autistic kid to move to one house to another".

Mothers described many negative outcomes during this time, most of which were psychosocial. Mothers who viewed their child's facility in a negative light worried about their child's well-being. For Jess, the facility where her child was placed "drove me more nuts than having Kate at home, because the [residential home] caused more problems than if I had had her at home". She went on to explain how "there was a lot of anger" directed at the facility; "[I was] to the point that I wanted to yank her out of there and bring her home".

Because of her child being moved around, Meg was worried about her child's well-being. She explained how this worry had a negative impact on her:

I was worried about every move, I was worried about every physical move, that there're all this new stuff that Roy had to get used to, and I wanted things to sort of stay the same as much as possible so that he would have some comfort from that.

Not only did multiple moves have a negative impact on mothers, as Sarah explains, her child with ASD was also impacted in a negative way due to being moved around too much. She explained: "He regressed a lot actually when he first went in [to care]".

Once the dust settled, parents began to talk about the joys that emerged following placement. For most mothers, their expectations for placement were eventually fulfilled. The following section depicts these joys.

Part 2 – Joys After the Dust Settled:

There are two huge differences: I get to enjoy him without being exhausted, alone, and trapped. I get to sleep at night. I have allies among the staff at the house, other people who care about my son. I get to participate in my career and my community without the guilt of feeling like I am not doing enough for Roy. I get to maintain my relationship with my son on his terms, instead of trying to fit him into my life. He has the structure he needs, and the excitement of coming home, and

then he can go back to [his group home] and calm down with the structure again. So I have the comfort of knowing that he has what he needs, and I can offer the fun stuff without being solely responsible for the hard stuff. (Meg)

After placement and after the dust settled, most parents described joys similar to the joys prior to placement. Mothers continued to describe the joy associated with times of perceived normality, such as spending time together with their child, watching their child develop, seeing their child happy, etc. The joys experienced after placement generally differed in the length of time they were experienced compared to the time prior to placement. For instance, whereas the joys prior to placement were often expressed as pockets of joy because they were “few and far between”, the joys after placement were described as longer. Mothers also described a variety of interrelated joys unique to this period. These included: feeling like they made the right decision, a shift back to normalcy, and having a life again, all of which can be characterized as mothers feeling a sense of control over their situation. In addition, all mothers who transitioned to this time viewed their situation as beneficial for them, their family, and their child with ASD. Lastly, some mothers expressed joy deriving from the actual facility in which their child was placed.

Most mothers described feeling like they made the right decision to place their child, not only for them, but also for their child with ASD. Meg, for instance, described how placement allowed her to do what “I can as a parent now”. She went on to explain, “I’m doing a better job of the things that I’m better at, like the advocacy and the focusing and trying to make things happen for Roy than I was before where I was just barely surviving”. Anne explained:

I just felt that he was in the right place; I felt we’ve made the right decision and that he was learning skills...So once I knew that or I felt in my heart that it was the right thing for us to do and it was the right place for him to be, then I really relaxed and just got on with my life and I decided to enjoy my life and the rest of us have been enjoying our lives.

Jess explained how placing her child into a treatment-care facility facilitated her child’s development. This development confirmed that she had made the right decision in placing her child. As a result of the treatment her child received, their mother-child interactions were of greater quality than prior to placement.

When she comes home, me and [my husband] will take her to the park or something, she'll run all over the place and now she says, 'mama, mama'. You know stuff like that, and you see her interacting with us better and she seems to know, 'ok I'm going home'. And then when she's here, she runs back and forth up and down the hall and whatever, and laughs and it just makes you feel a sense of calmness I guess, that she's so much happier and better.

She explained how her child is "...so much better and I can relate to her better, we can do things now without her going crazy". Other mothers also noted a strengthened mother-child relationship. Debra explained:

[Placement] made it possible for me to have a way more joyous relationship with Ben... When we share time or experiences it's just far more valuable. The energy that I save in the day to day, I can give back to him and be a more effective parent in spite of the fact that he doesn't live with me full time".

Mothers also described a return to normalcy following placement. For Shelly, things were on the whole "really good" after placement, once "everybody's sort of settled in. May's doing well and...the three of us sort of feel normal now...it took a while but now we kind of feel normal". She described this outcome after placement as a shift "back to normal":

Back to normal. I would say that...[the stressor-period is] kind of backburner, like it's no longer taking up emotional energy, space, time, whatever, and kind of just going on about my business. That's what I mean by normal, that it feels just generally that...it was like [my husband], her sister and I were in mourning for about, particularly the first three months after May left, and probably it sort of began to ease at that point and now... I don't feel like I'm mourning.

Most parents explained how they could "have a life again" after placement (Shelly). Meg explained how placement gave her the ability to "have a life...I also have my life back. I have some kind of reason to carry on". Others, like Jess, explained how she and her family enjoyed having a life again after placement, compared to before placement where "...we basically had no social life at home when she was there...", now "people can come over whenever they want and (her child with ASD) likes it. She thinks it's hilarious...big difference". She went on to explain, "we have a life and the life is better because when Kate comes home, it's a happier life, she sees her mom and dad are happier and the whole environment is happier".

Similar to having a life again, most mothers described a freedom to do things for themselves after placement. Debra explained:

Oh the freedom...just something as simple as sitting on the couch at night watching TV and having a craving for a rootbeer float and never ever before having had the freedom to get up, even if you're in your pajamas and get in the car and go get a rootbeer float, 'cause he was upstairs sleeping or whatever. That was a joy. Oddly enough, if I had a cold or the flu or whatever, having the freedom and time to actually get better. You know 'cause when you're sick and you're a parent, your kid's needs always still come first, whether they're sick or healthy, and so I think probably the first time I had a cold, there was a certain amount of joy in just being able to crash on the couch and get better.

Others expressed freedom for other family members: "freedom for the girls, freedom for us. That was the biggest thing...we were so confined to the house and car, freedom was the biggest issue" (Lisa). Anne explained, if "I wanted to go to the store and get some milk, I could go to the store and get some milk without having to take everybody with me or take Tom with me. If I wanted to go for a walk around the block, I just went... I wasn't looking at my watch wondering when my husband was coming home from work because I needed him to help with Tom". She went on to describe how this freedom impacted the entire family; "...just having that freedom, we could eat at six instead of five or we could not eat at all – everybody could fend for themselves for a night. I mean in all aspects it's just...the freedom; just feeling more freedom...and you know doing happy things with the kids like putting music on loud and dancing around the house, being silly and stuff like that. We could never do that with Tom around, it would just be too disturbing for him and then he'd react by lashing out at us".

Whereas some mothers viewed the actual facility in which their child was placed as a stressor, other mothers viewed the facility positively because their child was safe, happy, and being well cared for. Knowing that their child was "in a good place; his needs are all being met..." (Sarah) gave mothers a sense of joy. Shelly viewed the facility in which her child was placed as providing good quality of care. She explained: "I saw how much they understood her and liked her... she was having a blast and having fun and yeah, it's really nice to feel like other people like her and that she's well looked after".

Jess described simultaneous stressors and joys with the treatment-care facility in which her child was placed. In part 1 of this section, she described how the facility

“drove her nuts”. However, she also described a joyous aspect of the facility because it assisted in her child’s development. Jess explained:

The therapy was good, the treatment was good, the speech therapy...those things were all good. They seemed to be making a difference; she seemed to be getting better...She wasn’t pulling hair anymore, she wasn’t pulling people’s glasses off their face, she seemed to be tolerating noise.

The joy of seeing her child develop as a result of the facility’s treatment is reflected in her ongoing appraisal. Even though she was close to bringing her child home, she “thought, ‘well, she is getting better...’”, and decided to keep her in the facility.

In addition to experiencing joys during this time, mothers also talked about being able to cope. The following section explores how parents coped.

Part 3 – Parental Coping After the Dust Settled:

It’s like water finds its own level, it just takes a while once the storm is ended to try and level out. (Lisa)

What follows is a description of how mothers coped with the demands they experienced after their child left home. Some parents coped using similar strategies and resources as they did during the time prior to placement, such as seeking information, informal supports, etc. However, there were ways parents coped that were not mentioned prior to this time. Furthermore, unique to this time is a lack of formal supports used or available to help parents cope. Mothers coped mainly by staying connected to their child and redefining themselves as a mother of a placed child.

All mothers coped by staying connected to their child. Most mothers stayed connected by visiting their child frequently at the facility and having them over to their homes. Jess stayed connected by phoning the facility “at least once or twice a week and then I go get her as soon as I can”. Staying connected to their children helped the mothers to cope by knowing “what’s going on all the time” (Jess). For those who had concerns about the quality of care their child was receiving, staying connected included confronting the staff and advocating on behalf of their child. For example, Jess confronted the facility.

[I did] a lot of fighting with the management there. I was up there constantly fighting with the management. Screaming and yelling, I’d literally screamed and yelled and told them that I’m not putting up with this garbage, I don’t want to see

my kid go out, not dressed like that... And eventually it seemed like the more I complained, the more noise I made, the more action I got. That's what happened.

Mary had a similar experience. In order to cope with stressors brought on by the facility, she confronted the staff at the group home:

I asked for a communication book and I was told a communication book wasn't possible, it wasn't part of the job description for the workers there... So I said, 'well, I don't want to go this route but I do have the right to know what medication is being given to my child, and if I have to I will go to the (Commissioner)'. Well who wants to do this? ... And I wanted to meet the staff, just to say hello and to feel that I could drop in to see him [her child with ASD]. This should be his home, I should be his mother and be welcomed. ... They have just gone three hundred and sixty degrees. Or a hundred and eighty, which ever it is (laugh), since the accreditation meeting and now we're welcomed at the door... and there's a communication book... I think that it is extremely important if your child is in a group home, for you to be able to have access and communication and to know what's going on.

Some mothers redefined themselves as a mother of a placed child with ASD.

Shelly explained how she "had to redefine myself as her mother". Meg shared a similar sentiment:

I finally kind of reconciled myself to it, to him living down there and thinking, when families split up, the parent might live three hours away from the kid... That's kind of accepted. So this is like that and we're still his family and we still are involved in his life²⁰.

Conclusion:

I end this chapter with an examination of parental reflections on their entire caregiving experience. Despite varied outcomes after their child left home, all mothers described an overall positive experience, as they all expressed positive reflections on caregiving.

Section 6 – Overall Reflections on Caregiving:

... The biggest positive is just the learning that came out of that for us as a family, but for me in particular as a person. But I think it's shaped all of us, it certainly has shaped [my husband and daughter] as well as me... (Meg)

²⁰ For some, this might have started leading up to placement (see page 102 and Debra's experience coping with the time leading up to her child leaving the home).

Having a child with ASD resulted in both positive and negative consequences. These outcomes varied depending on the period of time mothers were talking about. While the literature on ASD focuses primarily on the stressors and more negative aspects associated with caregiving, mothers talked about a multitude of joys of caregiving as well. In other words, this study confirms that caregiving for a child with ASD is stressful, but it can also be joyous. In addition to talking about the stressors and joys of caregiving, due to the open-ended nature and structure of interviews, it was no surprise that mothers shared their reflections on their overall caregiving experience to date. All mothers spoke about personal transformation as a result of their caregiving years, including the one who was “stuck” in the stressor-period. This transformation included learning from their experience and growing as a person. It is important to note that these positive reflections are not linked to specific stressors, joys, or phase of caregiving but from their caregiving experience as a whole.

For example, Meg explained the learning involved in caregiving where she “learnt a lot about autism but I learned a lot about people, and I would have missed that...it was a really wonderful thing”. She continues:

I think the learning, well all of the learning about autism, I did lots of reading, I went to some workshops and courses and things like that...I learned empathy I think more than I'd ever had before. I think it made me a better (practitioner) in fact 'cause I learned a lot about grief, I learned a lot about chronic grief. I learned a lot about how important it is for people to make decisions for themselves, like I often have to talk to people about hard decisions...and I say to them things like...they have to make a decision where the next day when they wake up in the morning, they wake maybe with a sigh or maybe with some regret but they're not thinking oh my god, what have I done? Right, you need to be at peace with where they're going with themselves, not for me, but for themselves, like how they're going to feel about it ...I learned better how to not judge but to help people kind of cope I think.

Caregiving for Anne made her “stronger...I sort of became a fighter, just kind of like an advocate for the family but also for [my child with ASD]...So yeah definitely it makes you stronger. And it makes you tougher in a way”. Her experience also made her realize what is “important...So, you realize what's really important and don't sweat the small stuff”. Shelly described her child with ASD as being one of greatest teachers in life:

I mean I don't even know who I would be if I hadn't had May ...it's kind of a weird thing but in my life, she's been kind of one of my key teachers. She's kind

of forced me to kind of examine parts of myself that I don't know if I ever would have got to if I didn't have her. And, she forced [my husband] and I to kind of deal with issues that might have taken us years...It's been a struggle and sometimes I've hated her for it [but] nobody has taught me so much.

For Sarah, her child "...taught us patience and how to be understanding of people that are different..." She also described how "you just become more empathetic..."

My husband and I were asked that one time about the biggest thing that we got from Sam. I think it was the gift of patience 'cause I have patience unlimited you know... 'Cause once somebody's dumping milk out in your front yard (laugh), it's amazing how much patience you have.

One parent discussed forging new ground as a positive outcome of her caregiving experience. Tammy forged new ground as a result of developing a micro-board for her son. She explained:

To be one of a few families doing that for children is really empowering. So hoping that more children will have access to that because I think it's the wave of the future – individualized funding 'cause all these kids are individual and they all have specific needs.

All mothers described positive outcomes from caregiving for their child with ASD, an important element of caregivers' lived-experiences that has largely gone unexamined.

Conclusion:

The focus of this chapter has been on the experiences of mothers of children with ASD. More specifically, I depicted parents' experiences of caregiving for a child with ASD before, leading up to, and after out-of-home placement with a focus on the stressors, joys, and parental coping associated with these times. The next chapter discusses the findings as they relate to current research in the field of ASD. I return to the theoretical model proposed in Chapter II and revise the model in light of the findings. I also discuss the implications of this study, limitations, and future areas of research.

Chapter V

Discussion and Conclusion

Introduction

This study set out to explore the lived-experiences of mothers of children with ASD, with a focus on stressors, joys and parental coping before and after out-of-home placement. In doing so, the intention was to provide for a greater understanding of parents' lived-experiences as they relate to the difficulties and joys of caregiving for a child with ASD who is eventually placed in out-of-home care. Based on transcendental phenomenology purported by Husserl (1970), a three-core analysis process framed by the work of Moustakas (1994) was employed to analyze and report on the findings of this research. This chapter discusses the major findings reported in Chapter IV.

Section 1 of this chapter provides a brief summary of the major findings and, when available, situates these findings in current research. Section 2 concentrates on the theoretical implications of the findings, and relates those findings to the conceptualizations discussed in Chapter II. Section 3 discusses more practical implications to inform policy and practice. Part 4 briefly reports on other issues that are important to this type of research. This chapter concludes with a brief discussion on the limitations of this study followed by recommendations for future research endeavors.

Section 1 –Families Living With ASD

Five distinct but overlapping time periods emerged in the data reported here that were characteristic of parents' lived-experiences of caregiving for a child with ASD who was eventually placed. This section is separated into three parts: the time period prior to placement, leading up to placement, and after placement.

Prior to Placement:

During the time period prior placement (section 1 of Chapter IV), parents reported similar stressors, negative stressor-outcomes, and parental coping as those reported in other studies (DeMyer, 1979; Gray, 1998). For instance, most of the stressors derived from the caregiving role were directly related to the child's autistic traits (Dunn et al., 2001; Rivers and Stoneman, 2002; Weiss, 2002). Negative stressor-outcomes included

depression, anxiety, anger (Gray, 2002a), lack of life satisfaction, and feelings of exhaustion (DeMyer, 1979). These negative outcomes were consistent with more general psychosocial burdens found in other research on caregiving, such as “depression, guilt, worry, anxiety, loneliness, emotional stress and strain, lowered physical functioning, lower social functioning, worse general health” (Chappell et al., 2003, 366).

In order to cope with the demands of caregiving, parents used a combination of emotion-focused coping (including doing things for themselves and getting it from within) and problem-focused coping strategies (including limiting/modifying outings and information seeking) (Lazarus, 1996, cited in Gray, 2003: 632; Gray, 1998). They also utilized a multitude of resources. These included informal supports from spouses (Boyd, 2002), family and friends (Pruchio, 2003), and formal services such as parent support groups (Boyd, 2002) and respite services (Abelson, 1999).

Section 1 of Chapter IV focused primarily on some of the stressors external to the direct caregiving role, where current research is lacking. These stressors included being a single mother, being employed outside of the home, and/or having additional children, all of which placed added demands on the mother. While research has focused on how mothers as primary caregivers have career problems due to their caregiving role (Gray, 1998), there is limited research on how employment might act as a stressor on parents, which consequently impacts their caregiving role. By metaphorically flipping the lens and examining how employment might act as a potential external stressor on parents, the findings from this study suggest that it has the potential to place added demands on mothers, affecting their stress-coping process directly related to caregiving. With this said, employment can also help parents cope with the demands of caregiving.

Other external stressors discussed during this time prior to placement were stigmas experienced by mothers and negative appraisals of social support. Regarding the former, mothers experienced both felt and enacted stigma. In order to cope with these stigmas, parents either avoided social interactions or confronted the onlookers. These coping strategies were similar to those reported by Gray (2002b). In terms of social support, this study found that it is not the objective amount of social support given or received by caregivers that is important. Rather, it is how caregivers subjectively view the support that is important. This distinction was particularly clear when social support

was appraised in a negative light, despite the intent of benefiting caregivers. These findings support White and Hastings (2004) and Chappell et al.'s (2003) conceptualization of social support.

Section 1 of Chapter IV also focused on the joys of caregiving. When asked to discuss the joys of caregiving, all mothers expressed a multitude of joys both directly and indirectly related to the caregiving role. The most common joys included those that emerged through the relationship between mother and child, similar to those reported in other studies. Sometimes these joys derived from the direct caregiving role (Chappell and Litkenhaus, 1995 cited in Chappell et al., 2003; Folkman, 1997; Grant et al., 1998; Schwartz, 2003). Other times they derived from finding the "positive essence" in their child (Fleischmann, 2004), such as the positive personality traits. Other, more unique joys included discovering what was wrong with their child, their child making developmental gains, and both the mother and child developing bonds with others.

The joy of finding out what was wrong with their child might have derived from the unique characteristics of ASD and the difficulties associated with gaining a diagnosis on the autism spectrum (Mansell and Morris, 2004; Howlin and Moore, 1997 cited in Whitaker, 2002); once mothers knew what was wrong and were successful in gaining a diagnosis, it was joyous because they could now set out a pathway of care to help their child, understood what was wrong with their child, and had a label to attach to their child's disability to help explain what was wrong to others. Parents experienced joys when they saw their child develop possibly because it took away some of the ambiguity surrounding a diagnosis on the autism spectrum and not knowing their child's prognosis. These times were also joyous because they were viewed as normal times. Lastly, in the face of the sometimes isolating nature of ASD (Gray, 1998) and parental concerns about their child's future (Ivey, 2004), mothers expressed joy when they and their child developed bonds with others as these bonds might have counteracted these stressors.

Leading Up to Placement:

While past research has not focused on this specific population of caregivers and care receivers, the research reviewed in Chapter II provided specific factors that might lead to a parent's appraised inability to cope and subsequent placement. Characteristic of

this time is a transition from an appraised ability to cope to an appraised inability to cope. Similar to findings reported in other studies, factors that led to a parent's appraised inability to cope included the traits of the person with a disability (Bromley and Blacher, 1994; Freedman et al., 1997;), such as an increase in severity of negative behaviours, and family characteristics (Cole, 1986), such as a death of a family member and concerns about other family members' safety. In addition, outside influences acted as stressors on the family (Tausig, 1985), such as a lack of social support (primarily formal), and a shift in the service delivery system. Similar to past research findings (Bromley and Blacher, 1994; Freedman et al, 1997; Smith et al., 1995), this study showed that placement arose from complex processes rather than one specific factor. In other words, a combination of internal and external stressors with which a parent could not cope contributed to placement.

This research is unique because it offers a rich qualitative description of the transition from an appraised ability to cope to an appraised inability to cope. Differing from past research, the findings suggest that a lack of joys combined with parents' reappraisal contributed to their decision to place. A possible explanation is that when parents do not derive any joys and do not see any on the horizon, they may feel an inability to go on. As Ambert (1992) suggests, all parents are likely to derive fulfillment and happiness from their parental role. When this is not the case, placement might be the only option (see the next section for further discussion). Another possible explanation for placing comes from Yau and Li-Tsang (1999) and Winzer (1990) who suggest that parents who are unable to cope may be at the beginning phases of learning how to adapt and cope; they have not yet reached a stage of "mature adaptation" where they can accept the child, their disability, and themselves (in Cummins 2001: 87). While this understanding of parents' inability to cope places the responsibility on parents (one might even interpret it as blaming parents), this study suggests that it is a combination of factors leading to placement, not just the failure of parents to accept the child, the disability and themselves. To the contrary, accepting the child, the disability and themselves actually allowed some mothers to come to terms with placement; they realized that they were unable to provide for their child, and that placement might be best for all members of the family, including the child with ASD. This study does not blame parents for their

inability to cope, but depicts how they tried to cope, to the point where severe distress was experienced, until they were unable to go on. This research also described a social system at work that, in the eyes of mothers, failed to meet their needs and the needs of their child with ASD.

All parents experienced a time lapse from their appraised inability to cope to the time their child left home. During this period, parents experienced similar stressors and negative outcomes as during the time leading up to their appraised inability to cope. However, there are some stressors that were unique to this time period. Mothers talked about how the decision to place acted like a stressor as they wrestled with the decision (or indecision) to place their child. There were also concerns about the logistics of how placement would unfold.

An additional stressor of the placement decision was associated with felt stigma. Mothers experienced negative feelings about placing a child outside of the home that were externally imposed upon them. Perhaps this stigma was derived from the idea that society normalizes families living together (Cummins, 2001). While the findings did not indicate any enacted stigma experienced by parents during this time, the felt stigma made the placement process more difficult and taxing, making the decision to place nearly impossible. Parents dealt with the stigma associated with placement by coping from within by “reconcile[ing] myself” to the decision to place, and/or by seeking support from family and friends. A unique joy that emerged during this time was the joy of future hope, perhaps derived from an appraised return to normality in the future after their child left home. This joy might have also helped parents cope with the anticipated time leading up to their child leaving home and departure of their child. It might, therefore, be surmised that parents in fact did not “decide” to place their child with ASD, but had no option; it was their only way to cope. Despite feeling like it was their only choice, all parents described the decision or the indecision to place as extremely difficult. This finding supports the work by Freedman et al. (1997) and Smith, Tobin, and Fullmer (1995).

Post Placement:

All mothers described a stressor-period or what might be better described as a grieving period immediately following placement, similar to the time period leading up to their appraised inability to cope. This time was characterized by a lack of joys and an inability to cope. The major stressors associated were those related to the child leaving home. This period varied in length, from one month to over a year. Freedman et al. (1997) describe the decision to place as a time that is often accompanied by turmoil between family members and fluctuations in personal and familial well-being. Others describe it as one of the most emotionally arduous components of future planning, because of the difficulty in acknowledging the prospect of their child not remaining in their life-long home (Smith, Tobin, and Fullmer, 1995: 487). The findings here suggest that as placement becomes a reality, the difficulties associated with the decision to place are still present immediately following placement. In addition, mothers did not describe any specific ways of coping, but described just getting by.

Most mothers described a transition from the period immediately following placement to a period after the dust settled. Parents were now able to cope and to experience joys. However, despite the child no longer living at home, all parents still described stressors similar to those experienced before placement because all mothers were still very active in their child's life. These stressors and associated negative outcomes were not as severe or chronic because the mothers were no longer the primary caregivers. The mother who did not seem to transition to this time period talked about three interrelated factors: "feeling forced" into placement into a facility that was viewed in a negative light (prior to placement); believing that her child was receiving poor quality care (after placement); and stressors were chronic and did not subside with time after her child left home.

For the mothers who were able to transition into the period after the dust settled, they all experienced positive outcomes. These outcomes included a return to normality, feeling like they made the right decision to place, not just for themselves but also for other family members, including their child with ASD, and having a life again. I ended Chapter IV with a glance at how mothers reflected on their experience of caregiving. All mothers expressed positive reflections of caregiving. This suggests that despite the high

levels of stress these mothers experienced, they all gained something positive out of their experience.

Section 2 – Theoretical implications

The intent of this study was to explore parents' lived-experiences in caregiving for a child with ASD. I used the theoretical models of Lazarus and Folkman (1984), Folkman (1997), and Pearlin et al. (1990) to frame this inquiry. To illuminate some of the blind spots of these models, I incorporated insights from both models, resulting in a blending of the models. My intent was to provide for a broader examination of caregivers' lived-experiences by incorporating Pearlin et al.'s (1990) conceptual usage of secondary stressors external of the direct caregiving experience into Lazarus and Folkman (1984) and Folkman's (1997) model; this modified model attempts to account for events internal and external of the stress-coping process. Current conceptualizations of the stress-coping process suggest that positives outside of the stress-coping process are benign or irrelevant (Lazarus and Folkman, 1984), occur within the process as positive emotion (Folkman and Moskowitz, 2000), or stressors and joys co-occur within the stress-coping process (Folkman, 1997) (refer to figures 2.1 and 2.3). This represents a limitation of both models in that they fail to address the positives and joyous aspects of caregiving. This modified model elevated joys to the same level as stressors to highlight my intent to explore the joys of caregiving. Lastly, the concept of ongoing appraisal was introduced to counter the static representation of caregivers' lived-experiences in the aforementioned theoretical models. In light of the findings reported in Chapter IV, this study has potential theoretical implications.

The Joys of Caregiving

(The joys) just keep you going. Without the moments of comic relief, without the joys, without those moments of connection where he catches your eye directly for one minute and you actually have his gaze directly, without those things, you'd go stir crazy. Those are the things that feed you. I get a huge amount of strength from the tiniest little things. (Debra)

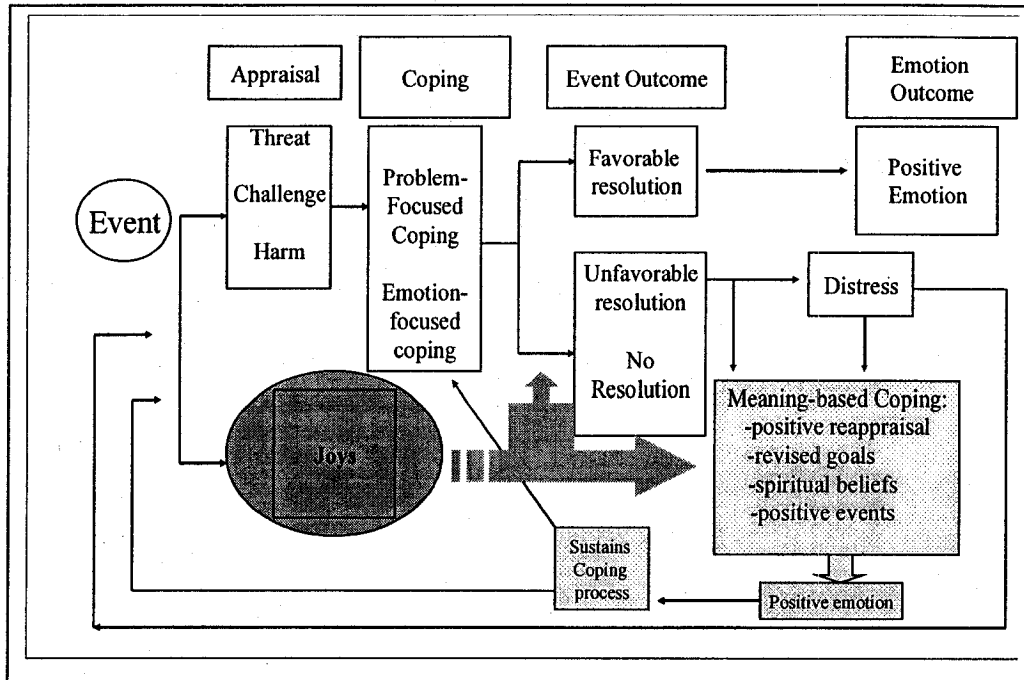
This study supports the findings in other research that caregiving for a child with ASD is stressful (Boyd, 2002; Burrell, Thompson & Sexton, 1994; Donovan, 1988; Dunn

et al., 2001) and recognizes the importance of examining the difficulties families face in caregiving for individuals with chronic conditions in order to assess what types of services and supports might assist families (Brinchmann, 1990; Larson, 1998 cited in Trute and Hiebert-Murphy 2002). However, breaking away from the majority of research in the field of ASD that focuses solely on the negative aspects associated with caregiving, all mothers in this study experienced joys throughout their caregiving experience, except in the time leading up to their appraised inability to cope and immediately following placement. These findings have theoretical implications on how the stress-coping process is conceptualized and utilized in research.

In Chapter IV, joys were not only expressed by mothers but were also occasionally discussed in relation to stressors and as helping mothers to keep on caregiving. This suggests that joys interact with the stressors of caregiving and caregiver outcomes. In other words, might affect how mothers experienced stressors and negative outcomes and had an impact on their ability to cope at different times. This discovery supports the importance of examining the joys of caregiving in conjunction with the difficulties, in order to gain a more complete understanding of caregivers' lived-experiences.

This study also revealed that joys do not only occur within the stress-coping process (Folkman, 1997) or derive from it (Folkman and Moskowitz, 2000); rather and in addition to, they occur outside of it, and interact with it. In other words, joys are not benign or irrelevant (see Figure 2.3), but are a key part of the stress-coping process and caregivers' lived-experiences. These findings contribute to and expand on the adaptational function of joys (Folkman, 1997) by shedding light on the importance of joys both within and outside of the stress-coping process (See Figure 5.1).

Figure 5.1 - Modified model of Coping, Accounting for *Positive Psychological States* and the Joys of Caregiving external to the stress-coping process:



Perhaps the importance of joys during caregivers' lived-experiences and their impact on caregivers' stress-coping process is most evident during the times in which joys were not present. These were times when mothers experienced the most severe distress. In other words, when parents did not experience joys, they experienced solely negative outcomes. Cummins (2001) and Grant et al., (1998) alluded to this same finding. Cummins (2001: 90) explains that most caregivers are able to describe positives derived from their caregiving role; when they are unable to do so, the demands of their role are likely to be intolerable. Grant et al., (1998: 66) further explain that without the joys of caregiving, it may not be possible for caregivers to feel as if they are able to continue encountering the stressful circumstances corollary to their role. As such, it might be concluded that joys are an integral part of parents' lived-experiences, to the point that when they are not present, parents may not be able to continue caregiving.

Ongoing Appraisal

Lazarus and Folkman (1984) and Pearlin et al. (1990) conceptually imply caregiving is a dynamic process between past, present, and future experiences, yet these processes in practice appear to be left in abeyance and outside the scope of current studies on caregiving. Based on the experience of the researcher and readings from Smith's (2005; 1987) institutional ethnography, and for the purposes of this study, the concept of ongoing appraisal was developed. This concept suggested that caregivers' lived-experiences are an ongoing process, where past events both within and outside of the stress-coping process impact present and future events via appraisal processes. In introducing the term ongoing appraisal, the hope was to allow the researcher to examine the more dynamic nature of caregiving, bringing these ongoing processes to the fore. Mothers alluded to the dynamic nature of caregiving throughout their experience. This conceptualization brought attention to this nature of caregiving and allowed for the illustration of how joys, stressors, and parental coping relate to past, present, and future experiences, to each other, and do not occur within a vacuum. This suggests that ongoing appraisal can be used as a heuristic device to shed light on caregivers' lived-experiences and perhaps add to the sociological study of stress by bringing attention to these ongoing processes.

By showing that stressors and joys do not occur in isolation of each other, this concept might contribute to literature on the positive aspects of caregiving for individuals with chronic conditions (Folkman and Moskowitz, 2004; Grant et al., 1998). Furthermore, the concept of ongoing appraisal along with qualitative descriptions, offers dynamic images and understandings of how caregiving is a process where events and experiences (internal and external) are part of caregivers' stress-coping processes. For example, when parents talked about the time leading up to placement, they described how their ongoing appraisal of their situation led to their reappraisal and ultimate decision to place. While this concept needs further exploration, in this study it drew attention to a dynamic process that might have otherwise been left in the dark.

A Modified Model Revisited:

I now return to a brief look at the modified model offered in Chapter II and suggest revisions as a result of the findings. The revisions are illustrated in Figure 5.2. Similar to the modified model in chapter II, this new model retains internal and external processes, exemplifying the blending of the theoretical underpinnings of Lazarus and Folkman (1984), Folkman (1997), and Pearlin et al. (1990). In light of the joys discussed by mothers and differing from the proposed model in Chapter II, joys are now inserted into the internal and external processes. These joys are not seen as “benign or irrelevant” as conceptualized in Lazarus and Folkman’s (1984) (see Figure 2.1) original model or as co-occurring only **within** the stress-coping process as proposed by Folkman (1997) (see Figure 2.3); these joys are now conceptualized as an integral part of caregiver’s stress-coping process and their lived-experiences. In other words, joys derive from the direct caregiving role and external to it. In addition to mothers discussing internal and external joys, they also talked about the impact joys had on their experiences. It is for this reason that I suggest the importance of conceptualizing joys as integral to a person’s stress-coping process and, more generally, overall caregiving experience. That is, mothers discussed joys as part of their experience of stressors and overall outcomes. In addition, joys might also facilitate coping (discussed below).

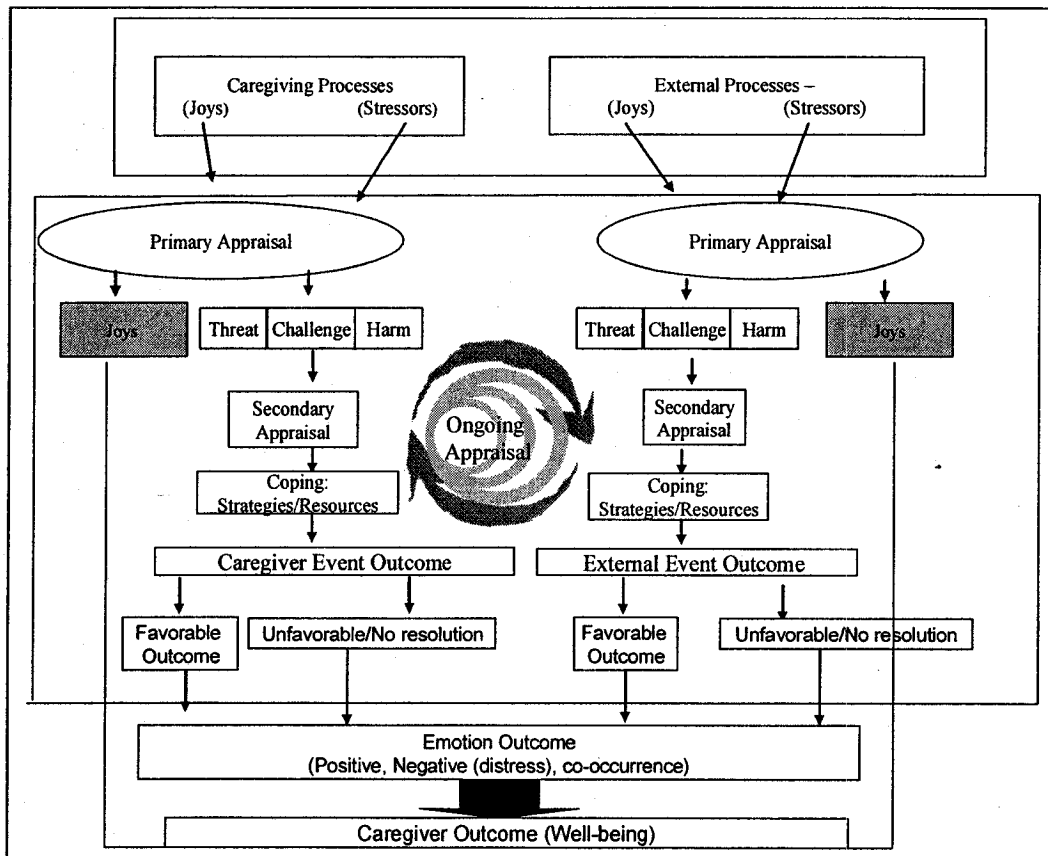
Furthermore, joys in this study were discussed in the same sense as stressors are discussed in stress-coping research today, as antecedents to joyous outcomes. This conceptualization was useful because it was aligned with the transactional model of stress and coping (Lazarus and Folkman, 1984). In other words, distinguishing joy(ors) from their outcomes provides for a better understanding of why and what experiences were joyous. Furthermore, this conceptualization of joys draws attention to the more sociological aspects of the concept and suggests that joys do not stand alone, devoid of other happenings; they focus on the individual’s view of the event. This conceptualization also allows for an exploration of how conditions arise and come to be related to each other (Pearlin et al., 1990). As a result, it is important to distinguish between joy(ors) and their outcomes, for a better understanding of the nature of experience.

While this research provides some conceptual insights into the joys of caregiving, the conceptualization of joys and positive/joyous outcomes still needs to be nurtured and developed. Research needs to further current understandings of the joys of caregiving and their role within and external of the stress-coping process. In addition, the researcher found it difficult to write about the joys of caregiving, due to the conceptual vagueness of terms used here. While the lack of knowledge on the joys of caregiving allowed the researcher to explore the joyous and positive aspects of caregiving without being limited by predetermined conceptual frames, in order to further this type of research, researchers need to be able to situate such findings into the theoretical frameworks of the stress-coping process of Lazarus and Folkman (1984) and Pearlin et al. (1990). Furthermore, is there a difference between joyous outcomes and positive emotions? Is one the antecedent to the other? These questions require further investigation and would shed light on the blind spots of this study.

Lastly, as the data suggest, ongoing appraisal was brought to the heart of this model, as parents' experiences were part of and a product of a process of ongoing appraisal. This move is key because it recognizes the dynamic nature of caregiving and suggests that experiences do not occur in isolation. Because the concept of ongoing appraisal is only in the pioneering stages of offering a more complex understanding of caregivers' lived-experiences, I suggest that it be used as a heuristic device. This suggestion, however, is not to limit its usage in future research. A fruitful area for future research is to explore how this concept is amendable to empirical measurement. For instance, this research provided qualitative descriptions of such ongoing processes. In doing so, this conceptualization attended to how events and experiences arise and come to be related to each other, providing insights into the stress-process model of Pearlin et al. (1990; 1981), the joys of caregiving, and allowed the researcher to account for the more dynamic nature of caregivers' lived-experiences. Other methodological approaches could shed light on the concept; for example caregivers could be asked to keep a diary of their experiences rather than retrospectively reporting them to a researcher. This would allow for analysis of ongoing appraisal through thought processes overtime rather than retrospectively. This might also address the magnitude and direction of such ongoing

processes as is indicative of the proposed model. A quantitative study might also eventually need to be designed to account for such processes.

Figure 5.2 – Modified Model Revisited:



The findings from this study suggest that only focusing on the stress-coping process and negatives associated with caregiving (Carmen, 2003; Diener, 1984; Johoda, 1958, cited in Ryff, 1989), offers a limited lens for examining caregivers' lived-experiences. Also, this lens confines and hinders the scope for exploring the nature of stressors, joys, and parental coping. This study, therefore, highlights the importance of examining both the positive and negative side of caregiving for children with chronic conditions, in addition to examining events not directly associated with the caregiving role. This broader conceptualization provides for a more comprehensive lens to explore caregivers' experiences.

In asking the question, “are current conceptualizations of the stress and coping process enough?”, I have found that they are not, and could be informed by the theoretical implications of this study. I also suggest that the implications of joys for caregiving and stress require further development (this will be discussed in Section 4).

Section 3 – Practical Implications

Many practical implications arise from this study that have the potential to inform policy and practice related to families of children with ASD and other chronic conditions. Of equal importance, it is the hope that this research provides future families of children with ASD a better understanding of the experience of caregiving. In an attempt to foster this understanding for future caregivers and families living with ASD, this section ends with some suggestions from the mothers to other mothers of children with ASD.

How families cope with the stressors associated with caring for a child with ASD not only influences the well-being of the family, but also possible life-gains that an individual with ASD can make (Schoplar and Mesibov, 1994). Current research on caregiving for children with ASD attempts to promote the use of successful coping strategies and resources in order to improve the quality of life of the caregiver and care receiver (Dunn et al., 2001; Gray, 1998; 1994). One practical implication that might inform research, services, and supports on successful coping is the need to promote the positives of caregiving both within service agencies and those caregiving for children with ASD and other disabilities. If services and supports are able to enhance the positive aspects of raising a child with autism (Hastings et al., 2005) by focusing on the joys of caregiving, parents might be able to cope more successfully with the difficulties of caregiving. In addition, it might be beneficial for services and supports to facilitate the joys of caregiving by drawing attention to the positive contribution their child with a disability makes to the family and caregivers (Pierpont, 2004). While Pierpont (2004) focuses primarily on positive outcomes of caregiving, the findings from this study suggest taking it a step further; in addition to focusing on positive outcomes, focusing on the joys that lead to positive outcomes of caregiving might identify and assist in the development of services, supports, and specific interventions that potentially facilitate improved outcomes for individual caregivers and the family as a whole.

While promoting successful coping strategies is important, it is also vital to have services and supports available that assist in parents' coping processes. This need was depicted during the time leading up to a parent's appraised inability to cope and the time period immediately following placement. A key factor that contributed to placement was the lack of services (Tausig, 1985). In other words, the findings suggest that parental coping and social supports are inextricably linked, with social supports acting as mediators of a caregiver's stress process (Pearlin et al., 1990); successful coping strategies without the adequate resources, such as formal services and supports, is not adequate. Furthermore, services and supports should be readily available, especially during times of severe distress. The findings of this study indicate that the opposite reflects reality; parents lost services and supports, or they simply were not made available, during the most stressful times.

On a similar note, all parents were still active participants in their child's life after placement. Most mothers described their child leaving home as a chronic stressor. Services and supports must recognize that caregiving does not stop with the placement of their child with ASD; parenting is a lifelong bond, which all mothers fought to keep after their child left home, despite the distress they experienced. First and foremost, mothers should not have to fight to maintain their bond with their child. Furthermore, supports are required at different points throughout caregivers' lived-experiences as both parent and child age and as new and unique challenges emerge. These supports should help facilitate successful coping for parents and improve well-being for both parent and child.

As previously suggested, the importance of joys was illustrated during the times when they were not present. A lack of joys could be an indicator of the current state of a parent's well-being or lack of well-being. Service providers and social supports might gain insight into ways to gauge parental well-being, in which case, policy and practice can proactively assist parents during times that might otherwise result in their appraised inability to cope.

This study also provided information on caregiver outcomes by gaining a better understanding of what might associated with positive outcomes compared to negative outcomes after placement. According to the findings, positive outcomes were more likely to occur for mothers who were able to transition out of the stressor-period immediately

following placement to the period after the dust settled. For families where a child is placed, supports and proactive measures need to be developed in order to facilitate an easier transition into life after placement and after the dust settles, in order to improve parental well-being. I envision these supports to include parent-focused and family-focused support groups. These groups should be readily available leading up to and following placement such that parents and other family members can talk with individuals who have gone through similar experiences and professionals who are familiar with the institutional component of the placement process. Supports should also have an individualized care component that recognizes the uniqueness of experiences.

Lastly, as a former behaviour therapist who provided care for children and adults with ASD, my hope is that these findings add to the work knowledge of those who are part of the service delivery system for children with ASD and families of children with ASD. For example, I know I would have benefited from this knowledge because it would have allowed me to understand what the mothers were going through and possibly assist in providing more/better support and compassion. Extending this implication, perhaps the findings from this study will assist the social worker, psychologist, psychiatrist, and others who work with mothers and children with ASD.

Suggestions from the mothers

Don't despair, everybody has challenges even with typical children so multiply that by a thousand and you have an autistic child. And, you'll have your good days and you'll have your bad days but you can do it. (Anne)

Each interview ended with warm-down questions that asked mothers to give advice to other mothers or future mothers who have a child with ASD. Parents were asked to give advice on caregiving for a child with ASD, for day-to-day coping, and on placing a child with ASD. They offered numerous suggestions. Starting with the time after receiving an ASD diagnosis, one mother suggested to “just go for it...Once you get your diagnosis, you figure out a plan and you go for it. Just don't give up”. Others advised on the importance of thinking positively about your child. Other suggestions surrounded improving the quality of care your child receives, the importance of dealing with a good general practitioner who is knowledgeable about ASD and the types of services and supports available, and being part of the planning process for your child at

every stage. Mothers also suggested the importance of spending time with other members of the family, ““cause you can kind of get lost if you don’t.”

Parents also offered advice on day-to-day coping. This included advice “not [to] stop banging on the door” of support whether it be from other parents “who have autistic children and have been there, done all the steps right from infancy” or professional care providers. In using formal services, some mothers described the importance of using the service to receive a break from caregiving. In order to do so, one mother in particular expressed the importance of finding “good respite care” that you can trust “so you come back rejuvenated”. Others described the need to advocate on behalf of your child and “remain that pillar for them”. Parents suggested to “get on the same page” as your spouse, and stay within the confines of your ability as a mother and caregiver while balancing the needs of your child with ASD with other family needs. Along similar lines, parents talked about the need to have an identity outside of the caregiving role. Lastly, one mother explained the importance of finding a reason to continue on while “embracing the caregiver role”.

Lastly, parents gave advice regarding out-of-home placement. One parent suggested that it is ok if you “really can’t cope. Don’t feel bad if you have to find somewhere else for them to live, even temporarily”. Also, parents suggested the need to focus on the positives that placement brings, such as having a better relationship with your child and family. Others described the placement decision as “very individual” and to make sure the type of placement fits your child’s needs.

Section 4 – Other Issues

Two other issues arose throughout; the first relates to the use of qualitative methods in the study of caregiving for individuals with chronic conditions and the study of stress; the second relates to the conceptualization of social support.

Kelso and colleagues (2005) describe qualitative methods as useful when exploring the lived-experiences of primary caregivers of children with disabilities. They write, “(qualitative methods) provide a systematic way of exploring complex issues that cannot be separated from the context in which they occur” (Kelso et al., 2005: 4). This study supports this finding. Also, this study shows how qualitative methods can provide

for a rich data set to investigate the complex nature of caregiving, and are a good means to explore how joys have an impact on and interact with the negative aspects of caregiving and other aspects of the stress-coping process. Furthermore, the open-ended nature of the questions allowed the participants freedom to express their experiences while focusing on specific aspects. In general, qualitative methods and, more specifically, open-ended interviews were a useful approach to assess the stresses and the joys of these caregivers and other aspects of their caregiving directly with the individuals who lived through the experience rather than through observation or interpretation (Bramston and Mioche, 2001).

In addition, the findings suggest that social support, both formal and informal, can act as stressors, in the form of help that is counterproductive because it is ineffective, excessive, unwarranted, and/or unpleasant (Rook and Pietromonaco, 1987 cited in Chappell et al., 2003), leading to additional stressor outcomes for caregivers. The findings also suggest that the determining factor in whether support is beneficial or not is how the person receiving the support appraises it. This is also true for respite, where respite as a service had a neutral or negative effect on parents who did not appraise respite as a break (respite as a stressor). As such, respite as a service had an impact on caregivers in a positive, negative, neutral way, or mixed way depending on the appraisal of the service. Furthermore, parents suggest that respite must consist of both a physical break and a mental break. When one is not achieved, a break from caregiving has not occurred, which supports the findings of Chappell et al. (2003: 368). Future studies need to account for the nature of social support by not straying from how it is conceptualized here. In other words, rather than conceptualizing social support as a service or support received, it needs to be viewed as an outcome based on how it is appraised by the receiver (Chappell et al., 2003).

Limitations

This study has several limitations. The sample, for instance, is a non-probability sample and is therefore not representative of the larger population (Bailey, 1987). The findings should therefore be used with caution. With this said, the intent of this study was to explore the lived-experiences of mothers of children with ASD, with a specific focus

on the stressors, joys, and parental coping before and after out-of-home placement and was not intended to be representational of the general population. This sample might have also been biased. While most mothers talked about positive outcomes after placement, one did not. Perhaps mothers who experienced more positive outcomes after placement were more likely to respond to the recruitment letter and be willing to participate than those who experienced more negative outcomes after placement.

In addition, participants were asked to retrospectively discuss events about parenting their child with ASD. Graham Gardner (2001) describes the process of remembering as very complex; he depicts memory as a metaphorical living field in which events and experiences are constantly changing and being assessed both internally and externally. He writes that memory should not be thought of as providing solely accurate accounts of experiences (Gardner, 2001). In addition, there are numerous reasons that participants may not tell the entire truth (see Gardner, 2001: 190-191), all of which lead to highly partial data (Gardner, 2001). It is therefore important to note that reflections greatly depended on the ability of parents to recall their past experiences accurately.

Retrospective data, then, can be associated with two types of errors: recall error and sample selection bias (Ayhan and Isiksal, 2004; Gershuny et al., 1994 cited in Jacobs, 2002: 537). This limitation was addressed in two ways: by collecting accounts from multiple participants to increase the validity of the findings (Ambert et al., 1995) and using appropriate cues to reduce recall errors. For instance, Ayhan and Isiksal (2004) explain that prompts or cues can improve recall memory about particular events. Beginning the interviews by discussing the early years of their child's development and working towards the present offered appropriate cues for participants to recall information, and thus it was hoped that participants had an easier time recalling past experiences of caregiving for their child with ASD. In addition, memory recall improves when events or experiences are more salient (Ayhan and Isiksal, 2004; Gardner, 2001: 192). It can be assumed that parenting a child with ASD is a salient experience for parents. Despite the limitations associated with retrospective data and personal accounts obtained by qualitative modes of inquiry, such interpretations and understandings are embedded within the social world and should not be disqualified. Instead, retrospective

qualitative data should be understood as contextually situated within the social realm, and influenced by a myriad of factors.

A social desirability bias, where respondents wanted to give a socially acceptable response (Esterberg, 2002), might have been present when parents were asked to talk about the joys of caregiving. As Cummins (2001) claims, parents will respond positively if asked a leading question about the joys of caregiving. He suggests that these types of questions can lead to a false understanding that caregivers' experiences lead to an overall positive experience. While this study may be critiqued for this type of bias, the same argument could be used when critiquing interviews that solely focus on the negative aspects of caregiving. In addition, parents did not describe joys every time they were asked to (joys were lacking during the times leading up to a parents appraised inability to cope and during the time immediately following placement). Furthermore, the findings suggest that all mothers derived joys and positive outcomes from their caregiving experiences in addition to experiencing negative and stressful aspects of caregiving. This mix of descriptions and experiences suggests that parents are not simply responding to what they perceive are socially acceptable when asked about the joys of caregiving. In other words, parents did not have any problem describing their experience as devoid of joys in some circumstances.

Another limitation of this study includes the singular focus on the experience of caregivers without a lens to explore and explicate how the experiences of these mothers connect to broader forms of social and institutional relations that are textually mediated. An institutional ethnographic study (Smith, 2005) would confront this limitation by exploring and explicating some of these limitations. Furthermore, this study has identified "lines of fault" (Smith, 1987) that could be taken up in an institutional ethnographic study as part of a study's problematic (see Campbell and Gregor, 2002).

An additional limitation of this study is the sole focus on the experiences of mothers as primary caregivers. While most research has focused primarily on mothers (Baker et al., 2003; Rimmerman and Limor, 2003), these findings do have implications for fathers as well as mothers. Baker et al. (2003: 227) explain:

The findings that there is more significant mother-father agreement in these families than in families not challenged with disability, and that the relationship

of child maladaptive behaviour and parenting stress is quite similar, adds some validity to past findings based exclusively on mothers.

Nevertheless, there is a need to explore gender differences in the stress-coping process and the overall caregiving experience (Hastings et al., 2005). This research would provide for a greater gender-based analysis of caregiving for children with ASD and perhaps shed light on different ways parents cope. A greater understanding of the experience of both parents would better inform services, supports and policies.

Areas of Future Research

It was nearly 65 years ago, in 1943, that Leo Kanner reported findings from eleven case studies of persons who had *autistic disturbances of affective contact*. Most current research in the field focuses on the medical and psychological characteristics of the disability (Pruchno, 2003; Wing and Potter, 2002), with a specific interest in early childhood development. While this study provides valuable information about an understudied population of caregivers and care receivers, it is limited in scope by focusing only on the caregivers of a population of individuals with ASD under the age of 18 years old. There is need to explore the psychosocial and institutional impacts of an aging population of individuals with ASD and their aged caregivers over the life course. Two significant factors indicate a need for this type research: 1.) Individuals with autism and other developmental disabilities are living longer; for the first time in history, individuals with disabilities are now reaching old age (Ansello, 1992; National Advisory Council on Aging, 2004); 2.) There is a movement towards deinstitutionalization where individuals with ASD and other disabilities are now living in the community. Because of this shift to informal care for these individuals, informal caregivers, often parents, are providing the majority of care over longer periods inside the home, leading to the description of them as perpetual parents or caregivers (Botsford and Rule, 2004: 423). While general population aging has garnered the most attention from researchers, aging with developmental disabilities, with respect to both caregiver and care receiver, has gone largely without comment (Sheets, 2005).

As the joyous aspects of caregiving is a relatively new domain of research, the findings from this study provide a rationale to further explore links between joys, social supports, coping, and appraisal processes for caregivers of children with ASD and other

chronic conditions. Furthermore, future research should investigate these links to determine how the facilitation of joys might affect caregivers' lived-experiences. For example, would the facilitation of joys decrease the stigma associated with caregiving? Also, as mentioned above, it is important to examine joys not only in relation to stressors, but also as an important factor throughout the entire stress-coping process. Because research that focuses on the positives of caregiving is still in its infancy (Grant et al., 1998), it is important to further explore whether joys mediate or moderate a person's stress-coping process.

The gender differences in experiencing joys should also be further researched as they relate to caregiving for children with ASD and other disabilities. In addition, while this study suggests that joys occur within and external of the stress-coping process, it is still unclear whether joys of caregiving are related to, or are a product of, event outcomes or successful coping strategies occurring within the stress-coping process (Grant et al., 1998). It follows, then, that the concept of joys needs further conceptualization.

When this study was initially conceptualized, there was a desire to gain a better understanding of the effects on parents of children with ASD who are placed in different types of facilities. Due to the lack of diversity in the sample size, it was difficult to explore this idea. As such, no notable differences were found between types of placement. However, the three mothers who placed their child in a treatment-care facility where their child received intensive interventions all described the joys of seeing their child develop after placement. Future research should investigate different types of placement (i.e. group homes, foster care, treatment-care facilities) and whether the type of placement affects the experiences of mothers. For instance, if the child experiences greater improvements in a treatment-care facility than in less treatment-oriented types of placement, how does this affect the mother's stress-coping process after the child leaves home? On a similar note, the benefits of applied behavioural analysis (ABA) therapy and other interventions need to be further explored in relation to the reduction or mediation of parental stress in the long run. Despite the co-occurrence of stressors and joys experienced by the two mothers running the ABA program, the long-term benefits might outweigh the short-term stressors.

With the introduction of the concept of ongoing appraisal, some mothers ongoingly appraised their child's disability. How parents appraise their child's disability and how it affects their interactions with their child and their caregiving experience is fertile ground for future research. For instance, how do mothers' views of their child's disability change overtime? How does this view affect their stress-coping process? The limited findings from this study suggest that how mothers view their child's disability has an impact on their appraisal of events associated with caregiving. However, the findings are inconclusive on this matter.

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Appendices

Appendix A

Recruitment Letter for Posting or Email

Volunteers Needed for Research on Autism

Michael K. Corman is a graduate student at the University of Victoria in the department of Sociology and has chosen to study the stresses, joys, and coping strategies of mothers of children with autism who live outside the home (either in foster care, treatment-care facilities, or residential group homes).

While most research in the field of autism focuses on the medical and psychological characteristics of the disability, other aspects of the disability, specifically the social aspects, need more attention. Michael's study will use semistructured interviews to explore the lived-experiences of how mothers cope with the stresses and joys of parenting children with autism. The working title of this project is "How Parents Cope with the Stresses and Joys of Having a Child with Autism: before and after placement".

This research is important because it will provide for a better understanding of parenting children with autism and the process by which placement occurs. If you consent to participate in this study you will, 1) get a chance to tell your story, and 2) contribute to research that seeks to inform policy and practice that has the potential to impact parents of child with autism and other disabilities.

Because of the nature of this research, Michael is trying to find a specific group of people to partake in this study. He is looking for mothers who have a child with autism between the ages of 6-20 who currently lives outside the home (in foster-care or treatment-care facilities) for a minimum of one year and reside in British Columbia or Alberta.

If you are a mother of a child with autism who is currently placed outside of the home, please consider being interviewed by Michael for this study **OR** if you know of a mother who has a child with autism who is currently living outside of the home, and you think she might be interested in this study, please pass this information on to her or contact me after you have received consent from the mother to pass on her contact information.

Mothers who voluntarily agree to participate in this research will agree to partake in a one to two hour interview consisting of open-ended questions aimed at exploring some of their experiences of parenting their child with autism. The interview will take place at a location and time most convenient to participants. Michael is requesting that the interviews be audio taped.

Confidentiality statement:

Participation in this study is completely voluntary. Participants can withdraw from this study at any time without any consequences or any explanation. In addition, participants are not obliged to respond to any questions that Michael will ask. Participant's anonymity

Appendix B

Recruitment Letter for the Society for Treatment of Autism

Letter to Mothers of Children with Autism through the Society for Treatment of Autism

Dear (potential participant)

You are being invited to participate in a study entitled "How parents cope with the stresses and joys of having a child with autism who lives outside the home" that is being conducted by Michael K. Corman who is a Master's Student in the Department of Sociology at the University of Victoria, British Columbia.

The purpose of this project is to study the stresses and joys and the coping process of parenting children with autism who live outside the home. Because of the nature of this study, I am looking for mothers who were the primary caregivers of their child prior to him/her leaving home. If you agree to participate, you will be asked questions (to which there are no right or wrong answers) that explore your experiences of parenting a child with autism. More specifically, questions will be aimed at exploring your stresses and joys of parenting a child with autism in addition to the coping strategies you used, before and after your child entered the residential program at the Society for Treatment of Autism.

Research of this kind is important. Such an investigation will have the potential to inform services and agencies to better accommodate parents of both children with autism and children with other disabilities. In addition, by exploring the stresses and joys of parenting children with autism, new parents of children with disabilities will possibly gain a more complete understanding of parenting and possible strategies and resources to further the coping process by which stress is mediated. Lastly, this study will ideally allow for informed policy geared towards families of children with autism as well as explore the nature of the stresses, joys and coping strategies associated with a child leaving home.

You are being asked to participate in this study because of your knowledge and experience as a parent of a child with autism. If you agree to voluntarily participate in this research, your participation will include a one to two hour interview consisting of open-ended questions aimed at exploring some of your lived-experiences of parenting your child with autism. The interview will take place at a location and time most convenient to you. I am also requesting that this interview be audio taped.

Your participation in this research must be completely voluntary. If you decide to participate, you may withdraw at any time without any consequences or any explanation of your reason to withdraw. If you withdraw from the study, I will ask to use the data that we have already obtained. However, if you decide that you do not want any data used, all data will be destroyed. In addition, you are not obliged to respond to any particular question that I may ask.

Your anonymity and any other person's identity that you discuss will be protected. No identifying information of you or your loved ones will be attached to your responses. Your responses will not be shown to anyone at the Society for Treatment of Autism or to anyone else. I will be the only person who has access to the data, which will be locked in a secure location, without any identifying features.

_____ has voluntarily agreed to participate in this study but has
agreed verbally and prefers not to sign.
(Print Name)

Print Participant's Name

Interviewer's Signature

Date

Yes I wish to receive a short summary of what the researcher learned from
this study.

A copy of this consent will be left with you, and a copy will be taken by the researcher

Appendix D

Face Sheet

Name:

Phone number:

Email:

Location of the interview:

Time:

Date:

Age of Child:

Gender of Child:

Diagnosis:

Age at Placement:

Type of placement

Age of Mother:

Work Status:

Marital Status:

Income:

Appendix E

Interview Guide

Introductory Questions-development of rapport:

Can you begin by telling me something about your family? How many kids do you have? How old are they? What are their favorite activities?

Question 1:

Being a parent involves both stressful and joyous events, starting during the early years of your child's development, can you talk about some of your stressful experiences prior to placement? Explain. (Give examples/events)

Stressful experiences? Explain (Give examples/events)

What was particularly stressful about these events? Why? Explain.

Focusing on a few stressful events (as discussed in question 1).

How did the stressors impact the joys?

Question 2 –Coping strategies

How did you deal with these stressful events?

Question 3:

What about the more joyous side of caregiving during the earlier years?

Why was this joyous? Explain.

Question 4:

How did the joys impact you?

Question 5:

Were there any events that were both stressful and joyous before your child left home?

Question 6:

What was going on in your life during this particular time (stresses and joys)? What was going on in the child's life during this event (either stressful or joyous)? (Before placement) Questions to be asked separately.

How did these events impact the events/your experiences with your child?

Questions are repeated:

Discuss the time period leading up to placement and after placement.

Warm-down questions:

What advice would you give to other parents who have children with ASD in terms of caregiving more generally?

What advice would you give to other parents who have children with ASD in terms of out-of-home placement?

What advice would you give to other parents who have children with ASD in terms of day to day coping?

Appendix F

Three-Column Approach (McNulty, 2001)

Data:	Coding:	Comments: