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By

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Abstract

Beyond Diagnosis: The Dynamics of Disability and Disruptions in Parenting

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Drawing on 11 months of field research with 127 SSI-receiving parents, this study examined the relationship between disability, economic hardship and parenting practices as well as the likelihood of families' involvement with child welfare services. Four main research questions were examined. First, what are the pathways through which parents apply for and receive SSI benefits? Second, what are the main health, economic and caregiving needs of SSI-parent families? Next, how do disability characteristics including the type of onset, the stability of symptoms and worry about outcome influence parenting and family well-being? Finally, do families with past child welfare involvement differ from families without past child welfare involvement on health, economic or caregiving measures?

While the health limitations reported by parents who received TANF prior to SSI were similar to those who did not, the age each group began to receive SSI was different as was the rate of child welfare involvement. Parents who transitioned from TANF to SSI were older at the time they were approved and were much more likely to report past child welfare involvement than parents without prior TANF receipt. Public and private sources of support reduced some types of material hardship but had little effect on parenting. Characteristics of disability such as an acute versus gradual onset were also not found to shape parenting once other variables were accounted for. Parenting constructs, including nurturance, follow-through with discipline and organization, did not predict the likelihood of child welfare involvement.

Economic hardships and parenting limitations were found to be most pronounced among parents with poor mental health, and this finding appeared to be related to a greater degree of social isolation. The development of a peer network, where parents can share their strengths and struggles and feel supported in their parenting role, may serve to reduce the social isolation of parents with mental health problems and improve their families' well-being.

Dedication

I dedicate this dissertation to my husband, Kenny, whose enthusiasm for my work never wavered, and to my boys, Brendan, Stefan and Robert. I love you all.

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Thank you to my dissertation committee, Professor Jill Duerr Berrick, Professor Susan Stone and Professor Susan Holloway, for their tremendous support, creativity and insight. Thank you, especially, to my dissertation chair, Professor Jane Mauldon, who introduced me to this area of research and encouraged me to pursue it.

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Chapter 1: Introduction

This study provides an initial look at the well-being of parents who receive income from the Supplementary Security Income (SSI) program. To qualify for SSI, applicants must have a disability that prevents them from engaging in Substantial Gainful Activity, generally defined as earning $1,000 or more per month, or is expected to result in death within 12 months. Additionally, SSI applicants must have limited resources, generally defined as less than $2,000 in assets such as savings accounts, life insurance or personal property. While the SSI program offers income to those who are unable to work due to disability, the level of support typically leaves families at or slightly below the poverty threshold. To date, little is known about how these families fare with the combined hardships of disability and limited income. Central to this research is exploring how parental disability shapes parenting practices in the context of limited income. Through interviews with a small sample of SSI-receiving parents, this research offers a first descriptive look at how parents understand their own disabilities and the ways disability influences parenting practices as well as family well-being.

There is little formal data on the number of SSI recipients that are parenting minor children; this information is not collected by the Social Security Administration. In a creative attempt to discern this number, researchers utilized data from the American Community Survey (Mauldon, Speiglman, Sogar & Stagner, 2012). Parenting rates were estimated for three low-income samples of adults with disabilities who reported SSI income.[1] The first sample (A) included adults that reported a disability that "makes it hard for them to work," the second (B) was comprised of adults reporting SSI-income of less than $11,000/year, and the third (C) used both these criteria. Table 1.1 shows the estimated parenting rates that resulted from these analyses. These percentages have been adjusted for two-parent households so as not to inflate the count.

Table 1.1
Parenting Rates Estimated for 3 Samples of Low-Income Adult ACS Respondents with Disabilities

	Sample A **Work-Limiting Disability**	**Sample B** **SSI Income<$11,000**	**Sample C** **Disability and SSI Income<$11,000**
Parenting rates among all SSI recipients age 18-64	19.2%	16.7%	17.1%
Parenting rates among all female SSI recipients 18-64	24.4%	22.5%	22.5%
Parenting rates among all male SSI recipients 18-64	12.9%	9.7%	10.6%
ACS sample: Men (n)	51,480	37,129	15,306
ACS sample: Women (n)	62,646	55,620	23,349
ACS samples used	2005-2007	2005-2010	2005-2007

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[1] Adults in all 3 samples had earnings of less than $4,000 and family income below 100% of Federal poverty level.

Applying the most conservative of these estimates, 16.7 percent, to the 2010 working-age adult SSI caseload (4.6 million) equates to an estimated 768,000 SSI recipients that are parenting minor children. In 2010, there were 74 million children in the United States and an average 1.8 children per family with minor children. Dividing the number of children by the average number of children per family equals nearly 40 million households with minor children. The number of SSI parent households are 1.9 percent of the total, meaning that nearly 1 out of every 50 children live with a parent who receives SSI.

Researchers are increasingly recognizing ways through which disability influences not just the person with the disability but other family members as well as the family as a whole. Comparing adolescents' feelings toward their single disabled parents to those of adolescents whose parents were not disabled, the adolescents with disabled parents reported more intense positive feelings toward their parents but this was moderated by anxiety. The more anxious the adolescents' felt about their parents' health and well-being, the more likely they were to report a positive perception of their relationship with their parent (Duvdevany, Moin & Yahav, 2007). Research with two-parent families has found that parental disability is linked to problems in family functioning. While maternal disability was associated with a less enriching home environment, paternal disability was associated with fewer family activities and less child monitoring, potentially due to the caregiving needs of the disabled parent (Hogan, Shandra & Msall, 2007).

The research discussed above revolves around a social rather than a medical model of disability. When stress and difficulties occur in a family headed by a parent with a disability, they are viewed as resulting not from the parent's disability per se but rather from interpersonal tensions and disparate needs, and these can be accentuated by a lack of understanding of the nature and course of the disability. Characteristics of disability, including the type of onset, stability of course and expected outcome, shape family members' understanding of and reaction to the disability. While some disabilities occur gradually and give families' more time to adjust to the changing circumstances, others have an acute onset and the families' situation immediately changes. The course may be stable, and the effects of the disability on family functioning predictable, or circumstances, abilities and needs may vary from day to day. Finally, family members may or may not expect the disability to result in premature death. These variables influence how families respond to the practical and emotional demands created by the disability (Rolland, 1999).

This study takes a systems approach to understanding disability, not focusing solely on symptoms and incapacitation but incorporating an understanding of how the circumstances surrounding the disability shape the family's response to the disability and the relationship between family members. Four main research questions are examined. First, what are the varying pathways through which parents with disabilities come to apply and qualify for SSI? This question considers the age at which parents applied for SSI, the time they spent on the application process, their subjective impressions of the application process and the relationship between SSI and other means-tested programs, most notably the Temporary Aid for Needy Families (TANF) program. SSI is an important safety net for low-income parents with disabilities and may, for many, replace the possibility of aid through the TANF program. Providing for material needs is a key aspect of parenting and, thus, the source and level of income is a fundamental variable in understanding parents' ability to provide for their children.

The second question seeks to identify the major health, economic and caregiving needs and supports of SSI-parent families. This question contributes to an overall assessment of how well the SSI program supports parents with disabilities and their children and what other supports are needed. The third question investigates the association between particular characteristics of disability (e.g., onset, course, incapacitation, and expected outcome) and parenting practices among SSI-receiving parents. Identification of these associations may suggest interventions to support parenting among SSI-receiving parents based on the inception, nature or course of their disabilities. Finally, the last question compares SSI-receiving families with and without prior child welfare involvement on measures of health, material well-being and parenting. Is the child welfare system working as intended with these families and intervening with those experiencing the greatest hardships? The first question is meant to describe parents' experience of the SSI application process and highlight the relationship between SSI and the Temporary Aid for Needy Families (TANF) program. Regarding the second question, all the parents are severely disabled by nature of qualifying for SSI. I hypothesize, however, that families who report greater social support will experience less material hardship and problems parenting than families who are more isolated. The third question draws on Rolland's Family Systems-Illness model (Rolland, 1999). I hypothesize that, regardless of diagnosis, parents who experienced a gradual onset, whose symptoms are stable, who understand and accept their current health status and who do not expect the disability to become terminal or severely incapacitating will show greater nurturance and consistency toward their children, report greater parental control, self-efficacy and family organization and experience fewer caregiving limitations and less parental stress. Regarding the final research question, I offer no hypothesis as this question is meant to explore the treatment of and outcomes associated with parents with disabilities in the child welfare system.

Chapter 2: Literature Review

This chapter has three main goals: (1) to consider the meaning of disability over time; (2) to provide information on SSI's development, eligibility criteria and approval rates; and (3) review what is known about the economic and caregiving needs of low-income parents with disabilities and their children. In the first section, I detail changes in society's response to caring for adults with disabilities, the evolution of the SSI program and how decreased stigma and greater income support combine with other forces to shape the likelihood that adults with disabilities will parent. In this section, I argue that the meaning of disability is largely influenced by the resources available to the family. In the second section, I move on to describe the SSI application, approval rates and rates of qualifying diagnoses among working-age adults, explore the possible pathways on to SSI for parents with disabilities, including the relationship between the SSI and TANF programs and, finally, estimate the number of SSI-recipients that are parenting minor children. The final section of this chapter synthesizes the research on the well-being of low-income parents with disabilities and their children, identifying common unmet economic and caregiving needs as well as essential supports and services, including the likelihood of involvement with child protective services. This review of the literature allows for an understanding of what it is like to parent with a severe mental, physical or learning disability on a daily basis.

The Historical Context

How we as a society understand disability is contextually driven. Who we consider disabled and how we care for them have varied over time. Based on the type and depth of disability as well as the time period, responses to the disabled have included institutionalization, forced sterilization, income supports and/or in-home care. When we consider disability in a historical context, it becomes apparent that how we understand and react to disability is in large part based on the time period in which it occurs.

This section of Chapter 2 addresses historical approaches to valuing and caring for people with disabilities as well as anti-discrimination legislative landmarks that shifted our understanding of and response to treatment and quality of life concerns. Three key questions are considered. First, how has the public perception of disability shaped disabled adults' treatment and rights over time? Secondly, how have current income support programs evolved to serve adults with disabilities? Finally, how likely is it that adults with disabilities will parent compared to past generations?

Throughout the 19th century and the beginning of the 20th, "disabled" referred mainly to those who could not safely live in the community due to severe psychosis or disability. These adults and children were taken out of their homes and institutionalized. This was referred to as "'indoor relief' – the 'warehousing' of these individuals in large institutions" (DiNitto, p. 144, 2003). Both county and state-run institutions housed the elderly, the indigent, the criminal, the mentally ill and the physically disabled.

Only the most vulnerable citizens were forced to turn to the hardship of indoor relief. The disabled were disproportionately represented in the institutionalized population because they could not support themselves through work. In many cases, the qualification for institutionalization was based more on status as a pauper than the existence of a disability (Munson, 1930). These institutionalized individuals had work limitations, no or limited family resources and did not have access to the technological and medical advancements that exist today. With these limitations, the social response at the time was to maintain the disabled and/or poor as efficiently as possible, with an emphasis on providing for basic needs and not attempting to treat or cure the disabling conditions.

The eugenics movement gained influence during the early 20th century, and one result was that some localities adopted policies permitting forced sterilization. The mentally ill, epileptic, blind, deaf, physically deformed, or those with chronic diseases were all at risk for forced sterilization (Pfeiffer, 1993). These laws resulted in large part from a general concern about the "fitness" and viability of the U.S. population. In 1907, Indiana became the first state to adopt a law permitting forced sterilization on "genetically-related" grounds (Pfeiffer, 1993). Other states, including Virginia, California, Washington, Connecticut and New Jersey, soon followed. Several of these laws, including Indiana's, were struck down as unconstitutional in the early 1920's.

The case of Buck vs. Bell brought the issue of forced sterilization to the Supreme Court in 1927 (Reilly, 1991). Carrie Buck, the plaintiff, and her mother Emma, had both been involuntarily committed and were thought to be feebleminded and promiscuous. Both had born children out of wedlock. Although less than one year old, Carrie's daughter was also judged to be feebleminded (Eugenics Archive). Upon hearing the case, Justice Oliver Wendell Holmes delivered the opinion of the court allowing the involuntary sterilization of Carrie Buck.

> It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind…Three generations of imbeciles are enough.
> — Supreme Court Justice Oliver Wendell Holmes, Jr., in Buck v. Bell, 1927

By 1930, forced sterilization laws were on the books in 33 states (Reilly, 1991). Oregon overturned the last of these laws in the 1980's, although no forced sterilizations had been performed in the 20 years prior. Over 63,000 forced sterilizations were performed in the 33 states that permitted them, with the bulk of these carried out in the 1930's.

For generations, people with disabilities had been grouped together in institutions. Richard Scotch, in a historical analysis of the disability movement, argues that this shared history created a collective identity among people with disabilities. This collective identity, encouraged by the African-American and women's movements, resulted in a disability movement that did not specify disability type. The plurality of needs at times created conflicting goals. "The practical accommodations [disabled people] require are different, and in some cases may even be inconsistent…the curb cuts needed for wheelchairs may make it more difficult for blind people to cross the street, for example" (Scotch, 1989, p. 385). The movement was based on a shared experience of facing stigma and social exclusion and intended to increase social respect for all people with disabilities.

With the disabled rights movement gaining support in the 1970's and challenging public perception of people with disabilities as dependent, legislative victories for disabled rights began to occur. An example of this is the Supreme Court case Wyatt vs. Stickney which required that individuals with disabilities be given the option to live in the least restrictive setting necessary and prohibited the inappropriate institutionalization of those without disabilities. Ricky Wyatt was a fifteen-year old who had been placed at a mental hospital in Alabama because of behavioral issues. He did not have a mental or physical disability but a court ruled he should be institutionalized due to his delinquent behavior. In his testimony, Ricky stated that he "slept on wet floors and was locked in a cell-like room with the only light coming from slats in the door" (Carr, 2004). He was heavily medicated and frequently threatened. The care he received in the institution appeared to only perpetuate his behavioral and emotional problems. In January of 1973, the Court's landmark decision in this case found that institutionalization should not be permitted unless absolutely necessary, in which case minimum standards of care were established.

In this same year, another important piece of legislation further expanded the civil rights of people with disabilities. The Rehabilitation Act of 1973, in Section 2a, made bold claims about the rights and capabilities of Americans with physical or mental disabilities:

> Congress finds that millions of Americans have one or more physical or mental disabilities and the number of Americans with such disabilities is increasing; individuals with disabilities constitute one of the most disadvantaged groups in society; disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society (Rehabilitation Act Amendment, 1973).

This act called for policies which reflect "respect for individual dignity, personal responsibility, self-determination…and inclusion, integration and full participation of the individual" (Rehabilitation Act Amendment, 1973).

Specific amendments to the Rehabilitation Act addressed vocational rehabilitation, research and training, rights and advocacy and independent living services. The purpose of Title VII, the independent living services and independent living centers, was to empower and integrate people with disabilities. In order to accomplish this goal, Title VII provided funding to states to expand and improve community-based housing options for the mentally and physically disabled.

Although this act was far-reaching in that it addressed a number of daily life concerns facing individuals with disabilities, the 1990 Americans with Disabilities act (ADA) went even farther to address challenges facing disabled individuals. This act defined an individual with a disability as one who has a physical or mental impairment that substantially limits one or more major life activities It supports civil rights for individuals with disabilities by banning discrimination in employment, public services such as education and health care, public accommodation, transportation, and telecommunications as well as other industries.

In summary, while adults with disabilities historically faced oppression and limited social and economic opportunities, they began in the 1970's to actively reshape public perception of disability through the disability rights movement and legislative victories such as the ADA. At the time, the idea that citizens with disabilities deserved equal rights in society was rather revolutionary. From a history of eugenics and institutionalization, the evolving emphasis on equal access and opportunity for the disabled was a dramatic shift. Along with a growing recognition of the rights and capacities of adults with disabilities, greater income supports for the disabled also developed in the second half of the 20th century. The next section chronicles the development of social insurance based on disability.

The evolution of income supports for the disabled. In the 1930's and on, public interest in a social safety net grew. The Great Depression, which began in the United States with the 1929 stock market crash, caused widespread unemployment and poverty. As a response, President Roosevelt laid out the elements of the New Deal that would create a greater degree of social responsibility for the care of all. As people saw their neighbors suffering and began to experience material insecurity themselves, growing support for social insurance developed which would help protect against common risks such as unemployment, old age, death of the family wage earner and illness and disability. Social insurance included unemployment, social security, survivor's insurance and, later, disability insurance.

In 1935, President Roosevelt signed the Social Security Act. Along with providing social insurance benefits for retired workers and the elderly, this act included federal payments to the blind. Fifteen years later, in 1950, the Social Security Act was amended to include Aid to the Permanently and Totally Disabled (APTD). Costs for this program were shared between the federal government and the states. States had authority over the administration of this program and eligibility and benefits varied greatly among the states. In passage of this act, Congress defined disability as "an impairment of mind or body which continuously renders it impossible for the disabled person to follow any substantial gainful occupation, and is likely to last for the rest of a person's life" (Berkowitz, 2000). This definition included not just a medical basis for disability but a social component based on activity limitations.

For those who had a history of work activity, Congress debated whether policy should emphasize rehabilitative services or cash support. The Eisenhower administration supported rehabilitation for the disabled, aiming to limit the amount of time any person spent in a disabled state. Roswell Perkins, Eisenhower's assistant secretary of health, education and welfare, stated, "the first line of attack on disability should be rehabilitation, in order that people be restored to useful and productive lives" (Berkowitz, 2000). In line with that goal, Social Security Disability Insurance (SSDI), which was passed in 1956, limited benefits to those 50 years of age or older. While prior legislation focused on aiding the poor disabled, SSDI marked the beginning of a system of insurance against disability.

The age-eligibility provision was eliminated in 1960. This represented the maturing of SSDI into an insurance scheme (payable for disability incurred at any age once someone was "fully vested" with 40 quarters). Key to this process was the debate over the definition of disability. SSDI insures against the onset of disability for those tied to the workforce. The definition of disability determines how and when someone becomes eligible to benefit from this insurance program. In this way, "the concept of disability…represents a politically fashioned compromise at any given time and place about the legitimacy of claims to social aid" (Stone, 1984, p. 27). Stone argues that the definition of disability "entails as much political privilege as social stigma" (Stone, 1984, p.28). Policy defines disability in order to determine eligibility to resources, including income support.

The APTD was given a new name and a new structure in 1972 under President Nixon. Under Title XVI of the Social Security Act, Supplemental Security Income (SSI) was established. SSI was created as a federal program, meaning that states could no longer determine eligibility or benefits. To be eligible for SSI, the applicant must be aged, blind or disabled with limited income and resources. Unlike SSDI, SSI qualifications do not require work history. Thus, it functions more as a system of social welfare than social insurance. A person is defined as disabled by the Social Security Administration if they are unable to participate in substantial gainful activity and his/her disabling condition is expected to last for a continuous period of 12 months or longer(Social Security Administration, 2010). Along with standardizing eligibility, SSI established minimum payments levels to beneficiaries ($710/month as of 2013). SSI recipients are usually eligible for Medicaid and (in all states except California) Supplemental Nutrition Assistance Program (SNAP) benefits.[2]

Although SSI standardizes eligibility criteria across all 50 states, what disabilities fit that criteria have changed over time. Prior to 1997, people who were disabled due to alcoholism or drug addiction were eligible for benefits (Social Security Administration, 1996). As of January 1, 1997, benefits were cut to anyone whose disability was believed to stem from alcoholism and/or addiction. This is a modern example of how definitions of disability change over time. Although people with alcohol and drug addictions may very well be unable to participate in substantial gainful activity for at least the next 12 months, the apparently self-inflicted nature of their disability makes them ineligible for aid, despite its disabling symptoms.

Legislative and sociological changes affecting parenting among adults with disabilities. Over the last 40 years, with support from legislation and growing awareness of the civil rights of the disabled, adults with disabilities are more likely than ever before to live independently in the community. This change is a direct result of evolving perception about what disabled adults are capable of and policy increasing access to income supports and housing. With greater community participation and less discrimination, more disabled adults have the opportunity to parent. Additionally, adults may become disabled or may be diagnosed with a disabling condition after they become parents.

Expanded access to resources and income supports improve the ability of disabled parents to continue to live at home and care for their families. Greater social support and acceptance may foster resilience in these families and programs such as SSI and SSDI offer an income guarantee for those with work limitations. Although the level of support from SSI and SSDI may be minimal, it is a guaranteed entitlement which will be provided monthly as long as the disability and work limitations persist. These social and policy changes do not necessarily mean that there are more parents with disabilities now than in past generations, however. Advancements in medical care and other types of technology have made it less likely that parents will be incapacitated after an accident or illness, while changes in the economy have reduced the number of jobs that are physically hazardous. Improved medical care may allow for complete recovery after illness or injury and better management of chronic conditions, while workplace regulations have led to safer working conditions. Figure 2.1 details factors increasing or decreasing the likelihood of parenting with a disability.

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[2] In California, the value of the SNAP benefits is included in the State supplement to SSI.

Figure 2.1
Factors influencing the probability of parenting with a disability in the 21st century

Increased:	Income support programs for disabled individuals
	Financial incentives for diagnosis of disability
	Medical and technological advancements increasing independence
	Greater social acceptance
	In-home care services
	Anti-discrimination legislation
	More effective treatments for infertility
Decreased:	Improved working conditions and safety legislation
	Better medical treatment preventing disability after injury or illness
	Better management of chronic conditions
	More access to, and wider choice of, effective contraception

Throughout the past century, responses to adults with disabilities have evolved from institutionalization to a focus on independent living in the community through income support programs and greater social acceptance. The odds are higher than ever before that adults with disabilities who wish to parent will have the opportunity to do so. The next section considers rates of SSI applications and qualifying diagnoses among working-age adults, estimates rates of parenting among SSI recipients and explores the varying pathways through which parents with disabilities may apply and qualify for SSI, highlighting the connection between the SSI and TANF programs.

SSI Application and Receipt

Across the United States, there are over 1,300 SSA state field offices (known as Disability Determination Services, or DDSs) where children and adults with disabilities may complete the SSI application. Additionally, SSI applications may be completed by telephone. Generally, the applicant is responsible for ensuring that all required documentation and evidence is provided to the SSA. For adult applicants, reports are commonly requested from physicians, psychologists and other health personnel, social workers and employers. If the evidence presented does not confirm the disability, consultative examinations (CE) may be sought (Social Security Administration, 2008). CE reports describe the SSI applicant’s diagnosis, prognosis, symptoms and pain level, results of laboratory and other tests and provide a statement assessing the applicant’s limitations.

Decisions on whether to approve or deny SSI applications are usually made by DDSs. According to the SSA, the decision typically takes 3 or 4 months from the date when the application is filed. If denied, the applicant has 60 days to appeal the decision. There are four levels of appeals: (1) Reconsideration, a complete review by SSA, (2) Hearing by an Administrative Law Judge; (3) SSA Appeals Council and (4) Federal District Court (Social Security Administration, 2012). Since the mid-1990s, 10 states have piloted an appeals process that omits the reconsideration step (SSI Annual Report, 2011). Once approved, benefits are paid from the month after filing the initial application which, in the result of a lengthy application process, can result in a considerable sum of back pay for the applicant. At any point in the application or appeals process, a SSI applicant may gain representation by an attorney. If the attorney charges a fee, it is limited by the SSA to the lesser of 25 percent of back pay or $6000.

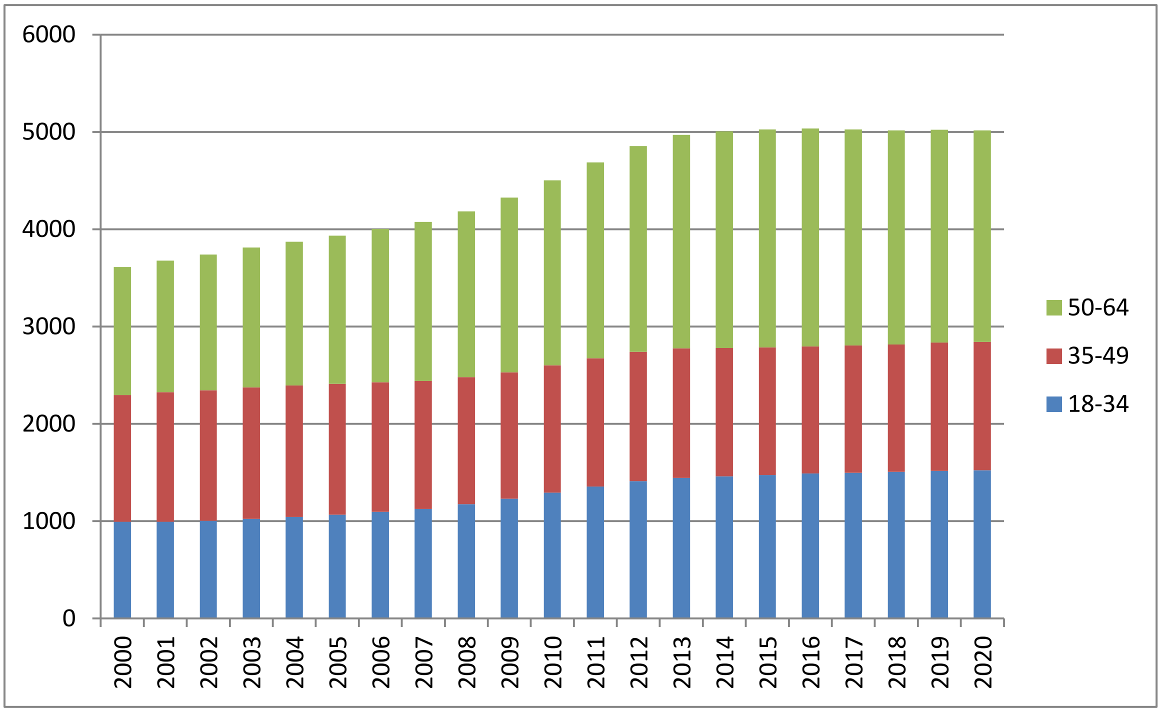
SSI applications and awards. On average, since the year 2000, 1.8 million working-age adults between the ages of 18 and 64 years apply for SSI each year (SSI Annual Report, 2011). Nearly 3 out of 4 of them, 73 percent, are denied. Of those that are denied, 40 percent file an initial appeal. Table 2.1 shows the number of applications filed and the number of awards made to working-age adults each year from 2000 through 2011. In 2010, over 70 percent of all awards to working age-adults were made to adults over the age of 40 years; nearly half (48 percent) were made to adults over the age of 50 (SSI Annual Report, 2011).

Table 2.1
Number of applications by and awards to working-age adults, 2000-2011

Year	**Number of Applications**	**Number of Awards**
2000	1,224,826	485,798
2001	1,324,057	504,366
2002	1,490,731	535,507
2003	1,608,391	539,127
2004	1,771,003	561,487
2005	1,850,002	560,960
2006	1,923,288	556,140
2007	1,945,464	563,094
2008	2,030,774	629,697
2009	2,285,852	694,242
2010	2,314,739	731,265
2011	2,235,535	719,080

SSI recipients. In 2011, 7.7 million individuals received monthly SSI benefits at a total cost of $47.8 billion (SSI Annual Statistical Report, 2011). Approximately 4.8 million beneficiaries were working-age adults between the ages of 18 and 64 years. Figure 2.2 details the number of working-age recipients from 2000 through 2020 (numbers are projected after 2010). In 2010, roughly 62 percent of all recipients were between the ages of 18 through 64 and this number is projected to remain fairly stable throughout 2020.

Figure 2.2
Number of working age SSI recipients, 2000-2020



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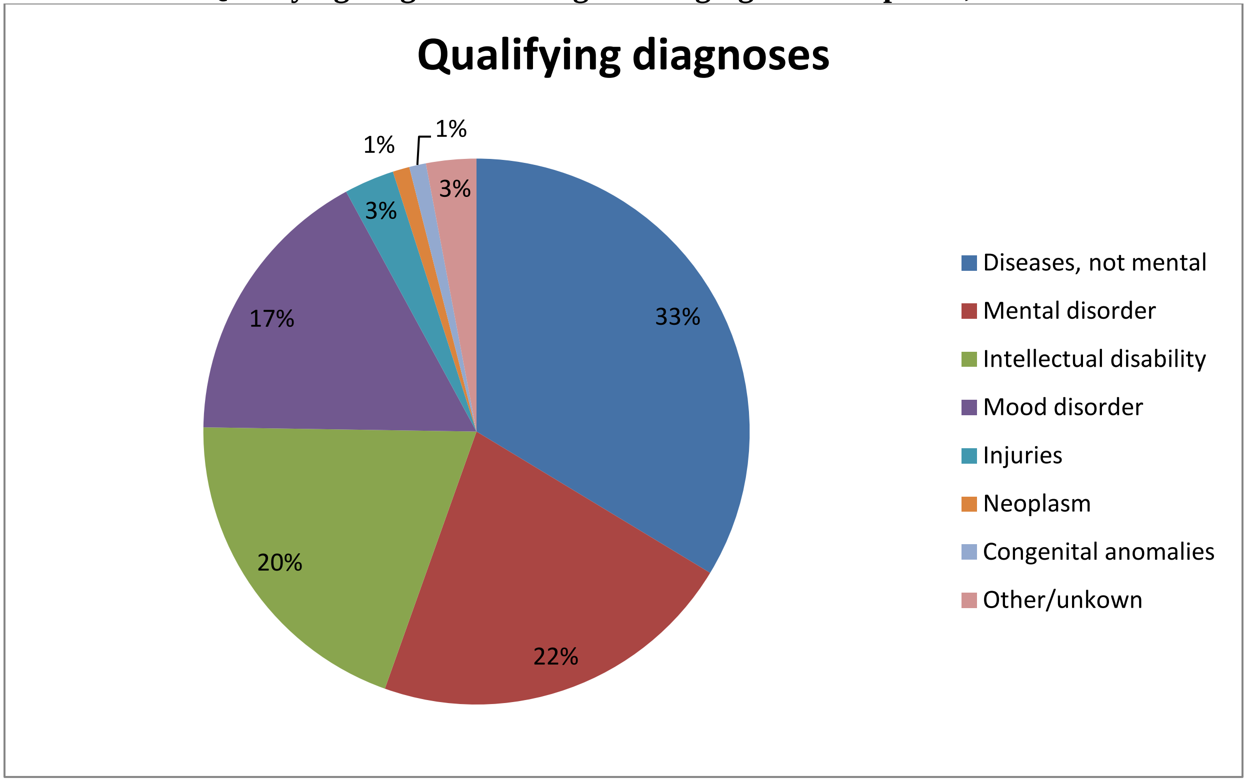
*Numbers in thousands

Source: 2011 SSI Annual Report

Qualifying diagnoses among working-age SSI recipients. Of the 4.8 million working-age SSI recipients in 2011, one-third (33 percent) qualified for SSI on the basis of physical diseases, most commonly diseases involving the musculoskeletal system, nervous system or circulatory system. Figure 2.3 reveals the break-down of qualifying diagnoses. Twenty-two percent qualified on the basis of a mental disorder (not including mood disorder or intellectual disability). Schizophrenic and other psychotic disorder were the most common type of mental disorder among recipients, making up over 40 percent of all cases of mental disorders. One in five recipients qualified on the basis of an intellectual disability and 17 percent qualified due to the existence of a mood disorder. Mood disorders are the fastest-growing category and accounted for most of the growth in working-age recipients between 2003 and 2011 (SSI Annual Statistical Report, 2011).

Figure 2.3
Qualifying diagnoses among working-age SSI recipients, 2011



Pathways to SSI. What triggers adults with physical and/or mental disabilities to apply for SSI? To answer this question, Estroff and colleagues (1997) followed a group of 169 adults who had recently been diagnosed with a psychiatric disability over 32 months to learn what influences people to apply for disability income. All adults were SSI-eligible due to limited work histories and earnings but had not previously applied. The authors speculate that there are three sets of characteristics that positively influence a person's decision to apply for SSI: (1) the severity of the impairment; (2) labeling by self and others as disabled; and (3) needs exceeding resources. When a person experiences mental and/or physical symptoms and activity limitations, self-identifies as disabled and has limited resources and supports, including social support from family or friends, he or she is likely to seek income from disability insurance.

Of the total sample, 47 percent applied for SSI or SSDI and 35 percent were approved. In an earlier quantitative analysis with the same sample, Estroff and colleagues (1997) found financial insecurity, the number of activity limitations and dependence on others to be positively associated with the likelihood of applying for and receiving disability benefits. As a program of "last resort," SSI appears to be serving those who lack financial support from work or family.

The TANF-SSI transition. The lack of education, work history and family support observed among SSI recipients is also descriptive of TANF recipients, suggesting some SSI recipients may turn to the TANF program prior to SSI. Previous research has attempted to discern the prevalence of disability among TANF recipients. Utilizing data from the National Health Interview Survey, Loprest and Maag (2009) found higher rates of disability among TANF recipients than among the general population on several different measures of disability. They found 1 in 20 TANF recipients reported self-care limitations, 1 in 10 reported limitations in routine activities such as household chores, and 1 in 5 reported movement limitations including difficulty lifting 10 pounds or climbing 10 stairs. These rates are between 4 and 5 times that found in the general population. Considering work limitations, 27 percent of respondents reported physical, mental or emotional problems limiting work. That percentage is 5.5 times the corresponding rate in the general population.

Once on TANF, parents with disabilities typically find it hard to meet work requirements and may end up timed out or sanctioned without any source of income. Up to one-quarter of all low-income single mothers are now "disconnected" from both welfare benefits and earnings (Blank & Kovak, 2008). Learning disabilities, depression and other mental illnesses and physical health problems have all been highlighted as key factors in explaining the number of disconnected mothers (Blank & Kovak, 2008). Even when disabled parents find a job, they often are unable to maintain work schedules and fulfill TANF work requirements over time, which may prompt an SSI application (Brandon, Hofferth & Hogan, 2008).

A number of researchers have attempted to establish the percentage of TANF recipients that successfully transition to SSI each year. While some estimate an annual transition rate, others calculate a transition rate over a period of years. Based on the type of measurement used, transition rates range from less than one percent in one year to nearly 4 percent over several years. Wamhoff & Wiseman (2005) estimate that in 2003, 0.4 percent of adult TANF recipients transitioned to SSI. Analyzing data from New Jersey's welfare reform initiative, Woods and Rangarajan (2003) found that 3.5 percent of study participants who were receiving welfare in 1997-1998 had qualified for SSI by 2002. Among women who left welfare between 2000 and 2002, Loprest (2003) concluded that 3.8 percent were receiving SSI in 2002. Finally, using data from California, Florida, New York and Illinois, Mauldon and colleagues (2012) found a transition rate ranging from 1 percent in 1 year to 4 percent after five years. These numbers indicate that a relatively small percentage of parents with disabilities successfully transition from TANF to SSI each year.

Parents with disabilities do benefit financially when they successfully navigate the SSI application process and move from TANF to SSI, receiving several hundred dollars more in aid each month (Speiglman, Mauldon & Sogar, 2010). Although little is known about how the larger SSI grants benefit families, data from a survey of San Francisco SSI parents whose children receives TANF are instructive. While one in four respondents reported having gone hungry in the preceding year, the corresponding percentage among TANF-receiving parents in California is close to twice as high (London & Mauldon, 2006; Speiglman et al, 2010). This comparison suggests that the benefits available from SSI (which are larger than in TANF) may enable parents who have transitioned to SSI to more often avoid hunger and, perhaps, other hardship

Rates of parenting among SSI recipients. A recent report on the composition and well-being of child-only TANF cases used data from the 2010 American Community Survey to estimate rates of parenting among SSI recipients (Mauldon et al, 2012). As official reports from the Social Security Administration do not provide data on parenting rates, the estimate based on the ACS is the best source of information available.

Among working-age adults with less than $4,000 in earnings and income less than 100 percent of the Federal Poverty Line, parenting rates are estimated for three samples: (1) adults reporting a work-limiting disability; (2) adults reporting SSI income of less than $11,000/year; and (3) adults meeting both of these criteria. Table 2.2 details the corresponding percentages for the total sample as well as by age-sex groups.

Table 2.2
Percent of SSI Recipients Age 18-64 Who are Living with Own Minor Children

	Parenting rates estimated for three samples, all adults age 18-64 that have own earnings<$4,000, income <100% of poverty[3]		
	Sample A Work-limiting disability	Sample B SSI income <$11,000	Sample C Disability and SSI income <$11,000
Parenting rates among all SSI recipients age 18-64	19.2%	16.7%	17.1%
Parenting rates among all female SSI recipients 18-64	24.4%	22.5%	22.5%
Parenting among recipient women by age group:			
Age 18-29	40.7%	39.8%	39.3%
Age 30-39	56.9%	53.3%	52.1%
Age 40-49	30.8%	26.3%	27.6%
Age 50-59	7.2%	6.6%	6.4%
Age 60-64	1.1%	1.2%	1.1%
Parenting rates among all male SSI recipients 18-64	12.9%	9.7%	10.6%
Parenting among recipient men by age group:			
Age 18-29	13.4%	9.9%	10.9%
Age 30-39	10.5%	8.6%	9.5%
Age 40-49	24.0%	17.7%	18.5%
Age 50-59	18.2%	12.9%	13.6%
Age 60-64	8.4%	6.3%	7.1%
ACS sample: Men (n)	51,480	37,129	15,306

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[3] The numbers in exhibit 5 are adjusted for two parent household so as to not duplicate children with two SSI-receiving parents who live in a single household.

ACS sample: Women (n)	62,646	55,620	23,349
ACS samples used	2005-2007	2005-2010	2005-2007

Source: Mauldon, J.G., Speiglman, R., Sogar, C. & Stanger, M. (2012). TANF Child-only Cases: Who Are They? What Policies Affect Them? What's Being Done? Retrieved from: http://www.cfpic.org/pdfs/TANF-Child-Only-Cases--The-Report-12-19-2012.pdf.

In 2010, there were 4.6 million working-age SSI recipients. Applying the most conservative parenting rate (16.7 percent, sample B) results in 768,000 SSI recipients who are parenting minor children.

Parenting with a Disability

There are varying routes through which parental disability might affect parenting. Disability, whether mental or physical, may disturb parents' ability to physically care for their children as well as alter emotive and cognitive parenting tasks (Evans, Shipton, & Keenan, 2005; Mazur, 2008; Kahng et al, 2008; Oyserman et al, 2005). Parents who suffer from physical disabilities such as mobility problems may be unable to complete basic caregiving tasks such as diaper changing or meal preparation. Research with mothers experiencing chronic pain found that the pain level was inversely associated with the mothers' abilities to fulfill fundamental caregiving responsibilities (Evans et al, 2005). Maternal depression has also been linked to an increased risk that children's physical needs will not be met (Lovejoy, Graczyk, O'Hare, & Neuman, 2000).

An essential task of parenting is the development of a strong bond between the parent and child. Low parental warmth is associated with child maltreatment as well as poor child emotional health (Brown, Cohen, Johnson & Salzinger, 1998; Davidov & Grusec, 2006). While disability may limit the expression of physical affection, it may also disrupt communication between parents and children and threaten the development of a strong emotive bond.

Cognitive aspects of parenting include discipline, parenting self-efficacy and stress management (Azar, Lauretti & Loding, 1998; Benjet, Azar & Kuersten-Hogan, 2003). Parents experiencing extreme pain, depression or delusion or severe incapacitation might be irritable or unable to negotiate limits and may respond to their children's needs or wants with aggression. For example, empirical evidence suggests that parental mental health status is inversely associated with use of corporal punishment (Chung, McCollum, Elo, Lee & Culhane, 2004; Strayhorn & Weidman, 1988).

Parenting self-efficacy refers to parents' own views of their caregiving abilities. Parents with high self-efficacy feel they are capable of meeting the demands of parenthood and successfully completing the required tasks. Basically, parents who believe they are good parents are more likely to actually be good parents. Low parenting self-efficacy has been linked to problematic parenting, including harsh discipline practices as well as an increased risk for child abuse and neglect (Sanders & Wooley, 2005; Slack et al, 2011; Stith et al, 2009). Both physical and mental health disabilities are associated with lower parenting self-efficacy. Mothers experiencing depression have been shown to have more negative perceptions of their parenting ability than non-depressed mothers, resulting in less sensitivity towards children's needs and greater impatience, rigidity and withdrawal (Teti, O'Connell & Reiner, 1996). From interviews with physically disabled parents, Mazur concluded that physical limitations were associated with weaker parenting self-efficacy (Mazur, 2008).

Finally, disability might result in excessive stress if the demands of parenting exceed the resources available to meet those demands (Deater-Deckard, 1998). Disability might increase stress by decreasing resources. Material deprivation may cause children's needs to go unfulfilled, increasing stress and triggering parents to feel as if they are failing their children. As disability may in some cases interfere not just with the parents' ability to provide for their children but also with the emotional bond between parent and child as well as discipline style, are parents with disabilities more likely to be involved with the child welfare system?

Relationship between parental disability and involvement with Child Protective Services. Although research is limited, recent empirical evidence suggest that parents who suffer from chronic health or mental health problems are more likely than non-disabled parents to abuse or neglect their children (Slack et al, 2011; Stith et al, 2009). Correspondingly, research with parents with disabilities in the United States has found relatively high rates of CPS involvement. A study by Joseph and colleagues (1999) explored, first, the prevalence of mothers among a sample of severely mentally ill women and, secondly, what proportion of mothers had lost custody of their children. Women were recruited for this study from an urban psychiatric hospital and thus are not representative of the broader group of women with severe mental illness but rather those with a history of institutionalization. Thirty-eight percent of mothers in this sample reported that their children were in some form of foster care. Even higher rates have been found in studies with mothers with schizophrenia (48 percent) and parents with intellectual disabilities (46 percent) (Accardo & Whitman, 1989; Miller & Finnerty, 1998).

More recent research utilized Philadelphia's Medicaid files to generate a sample of mothers with a psychiatric diagnosis and compare the histories of child welfare involvement in this sample to child welfare involvement among mothers without such diagnoses. The mentally-ill mothers made up 11.6% of the 4,827 mothers on Medicaid in Philadelphia (Park, Solomon & Mandell, 2006)., The researchers determined that 7.2 percent of Medicaid enrollees had a serious mental illness while 4.4 percent had other psychiatric diagnoses. Mothers with serious mental illness were over three times as likely to have experienced child welfare involvement in the previous five years as those without mental illness. While 14 percent of mentally ill mothers had been involved with child welfare services, the corresponding rates for mothers with other psychiatric diagnoses and without mental illness were 10.8 percent and 4.2 percent, respectively. These estimated rates of child welfare involvement of mothers with psychiatric illness, although still high, are lower than those reported by earlier studies. This difference is likely due to the use of administrative data examining child welfare involvement in a five year period versus self-reports determining lifetime prevalence (Park et al, 2006). It is also possible that the participants in the survey research were more severely disabled and as a result experienced greater difficulty parenting, as it is likely that a greater percentage of the survey respondents were hospitalized.

Studies of child protective hearings in Australia also suggest that disabled parents are disproportionally represented in the child protection system. A 2003 study by Llewellyn and colleagues examined 285 court files from child protection hearings at two Children's Courts in New South Wales. They found close to 30 percent of the parents involved in these hearings had a psychiatric or intellectual disability. The rate of these disabilities in the general population is between 2.6 and 5.4 percent (psychiatric disability) and less than 1 percent (intellectual disability), indicating these parents are over-represented in the court system ("Disability, ageing and carers," 2009; Llewellyn, McConnell & Ferronato, 2003; McConell & Llewellyn, 1998;

McConnell, Llewellyn & Ferronato, 2000). In studies with intellectually disabled Australian parents, Bowden (1994) and Booth and colleague (2005) found rates of CPS involvement ranging from one-quarter to one-third.

Conclusion

Disability has meant different things at different times. The limitations associated with a mental or physical illness have varied as a result of the medical, financial and practical supports available. Since the 1970's, there has been a focus on the deinstitutionalization of the disabled as well as greater access to income support programs. These changes have increased the likelihood that parents with disabilities will be able to live independently with their children.

The existing data shows that parental disability is associated with greater dependence on public aid (Brault, 2008; Jans & Stoddard, 1999). Parents with disabilities face greater material hardship than non-disabled parents, frequently in the form of food insecurity (Parish et al, 2008). Additionally, they are more likely to be socially isolated. These hardships combine with physical and/or mental limitations to potentially result in high levels of stress and reduced self-efficacy. Stress and self-doubt can negatively impact parenting on both a cognitive and affective level.

As disability may in some cases interfere not just with the parents' ability to complete daily jobs of parenting but also with the emotional bond between parent and child, are parents with disabilities more likely to be involved with the child welfare system? Research from Australia and the United States indicates that parents with intellectual as well as psychiatric disabilities are over-represented in the child welfare system. It would be helpful to know more about the case outcomes that occur when the parent is disabled. CPS involvement might prove to be a benefit for families when the contact results in greater connection to needed services and supports Social isolation accompanies disability in many cases, such as a parent with a mobility problem or one whose depression keeps her locked inside. A CPS contact can be the first step in decreasing that isolation, bringing in (theoretically) a concerned and competent case worker. In California, as in most states, a central mission of CPS is to connect families with supportive services. These services may include health and mental health care, housing assistance, emergency food or clothing and early childhood developmental programs.

The review of the literature highlights the caregiving and material challenges that plague many parents with disabilities and their families. The literature identified the problems associated with being a parent with a disability: low self-efficacy, high stress, material hardship, and caregiving limitations. However, many, if not most, SSI-receiving parents are good parents, meeting the physical and emotional needs of their children and helping them thrive even in impoverished environments. A major gap in the literature is in understanding how and why some parents with disabilities fare better than others with similar disabilities. Is it a difference in social support, psychological characteristics, circumstances surrounding the disability or something else? This research contributes to the field by delving into the myriad of factors that shape parenting and family well-being to increase our understanding of how parental disability affects family functioning.

Chapter 3: Conceptual Framework

Theories of Effective Parenting

Researchers have used diverse measures to describe and define "effective parenting". Two central concepts have been attachment and control. In the 1950's, attachment theorists John Bowlby and Mary Ainsworth evaluated parenting based on the development of a secure attachment between mothers and their babies (Bretherton, 1992). The mother's prompt and correct response to her baby's cues forged a strong bond between mother and baby. This bond allowed the baby to feel secure, free to explore the world knowing there was a safe home base to come back to. When a secure attachment was not formed, Bowlby and Ainsworth concluded the child would develop behavioral problems and have trouble forming successful relationships as an adult

In Diana Baumrind's classic analysis of parenting styles, quality parenting is largely determined by the parents' approach to discipline (Baumrind, 1989). She interviewed numerous middle-class parents and concluded that the parents' style of discipline was linked to child self-reliance and maturity. Baumrind defined three parenting styles consisting of authoritarian, permissive, and authoritative. A fourth style, uninvolved, was later added (Maccoby & Martin, 1983). Authoritarian parents were highly controlling, attempting to mold their children's behaviors and attitude to a set standard of conduct. With firm enforcement and little room for negotiation, their children were found by Baumrind to be "relatively lacking in independence and dominance" (Baumrind, 1989, p. 353).

Permissive parents, on the other hand, give their children a high degree of freedom and permission to do most everything they want. They are warm and caring with few rules and restrictions. They do not attempt to shape their children's behavior but instead aim to fulfill their children's wishes and desires. Baumrind found the children of permissive parents to be immature and, similar to the children of authoritarian parents, lacking in self-reliance and independence (Baumrind, 1989).

Uninvolved parents pay little attention to their children. They do not set limits or standards for behavior, and ignore the resulting behavioral consequences. There is little warmth and support and infrequent communication between parents and their children. Children of uninvolved parents have been shown to fare the worst across a variety of domains, including social competence, academic achievement and psychological adjustment (Glawgow, Dornbush, Troyer, Steinberg & Ritter, 1997).

Baumrind's research found that the best child outcomes resulted from authoritative parents. These parents enforce rules but educate their children on the reasons behind them. "Authoritative parents are affectively responsive in the sense of being loving, supportive and committed and cognitively responsive in the sense of providing a stimulating and challenging environment" (Baumrind, 1989, p. 354). According to Baumrind, these children were more friendly, achievement-oriented and self-reliant than children from families without authoritative parents. Although critics of this theory say it is not cross-cultural and only applies to the white, middle to upper-class families she sampled, it does emphasize the importance of communication in effective parenting. Similar to attachment theory, the bond created between the child and parent legitimizes the parent's authority.

What role might parental disability play in these models of effective parenting? Bowlby and Ainsworth's theory focused on the development of a secure attachment between the mother and her infant. If the mother is unable to hold the baby or respond to his/her cues within a short window of time, a lack of attachment might result. A mother who cannot change diapers or bottle or breastfeed because of a physical disability will have fewer opportunities to cultivate a physical bond with her infant and face greater risk of insecure attachment. Mental health problems might distort the meaning a mother attributes to her baby's cues. This disruption in communication could also result in insecure attachment.

Baumrind's theory of parenting revolves around the parent's discipline style. Authoritative parenting requires more energy and engagement than uninvolved or permissive parenting, involving firm rules and set boundaries. Authoritative parenting also entails a greater degree of flexibility and democracy than authoritarian parenting. Symptoms of disability, possibly including pain, fatigue or depression, may limit parents' engagement and flexibility and diminish parenting quality as defined by Baumrind

More recent research has considered parenting capacity as providing the causal link between parental disability and child outcomes (Drew, 2009). Studies have defined parenting capacity in two ways – as parenting efficacy and as parenting competence (Drew, 2009). Parenting efficacy consists of the daily tasks of parenting such as carrying a small child, providing adequate, healthy meals and transporting them to school and other outings (Evans et al, 2005). Parenting efficacy does not take into account the multitude of parenting responsibilities that go beyond providing basic care, such as emotional support and academic assistance. When a physical or mental health disability prevents a parent from completing these instrumental tasks, it can have negative effects on the child's development as well as the parent's mental state, as the inability to adequately care for their child may produce psychosocial distress (Drew, 2009). This definition of effective parenting is somewhat biased against parents with disabilities who may be unable to perform caregiving tasks themselves but arrange for others to care for their children's needs.

Parenting competence goes beyond parenting efficacy to consider the emotive component of parenting (Drew, 2009). Parenting consists not just of basic caregiving tasks but also the development of an emotional bond between parent and child, as conceived by attachment theorists. Competent parents care not just for basic needs but bond with their children, developing a secure attachment. Unlike basic caregiving tasks such as diaper changing, the emotional work of parenting cannot be readily delegated. The next section introduces theories on psychological processes that may moderate the relationship between disability and successful completion of basic and emotive parenting tasks.

The Relationship of Disability to Parenting

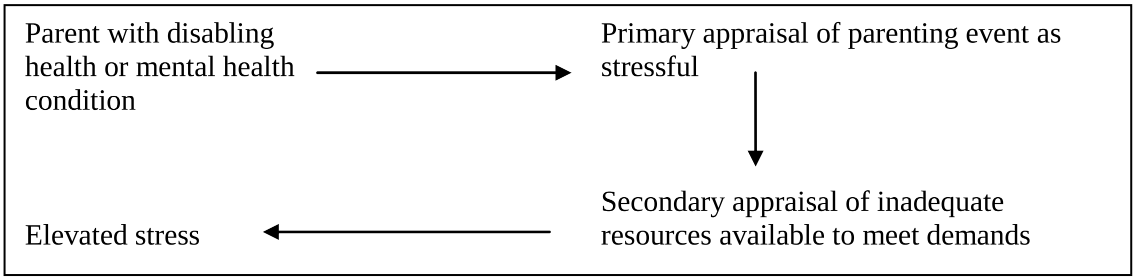
The models of "good" parenting presented in the previous section demonstrate parenting tasks that are important to fostering healthy child development. This section uses two different theories to explore the possible impacts of disability on parenting. Existing research suggests that stress and self-efficacy are key explanatory variables in the relationship between disability and a parent's psychological well-being (Evans et al, 2005; Kahng, Oyserman, Bybee & Mowbray, 2008; Katz, Pasch & Wong, 2003; Mazur, 2008; Wilson & Crowe, 2009). After detailing the transactional model of stress, I move on to consider self-efficacy theory as well as a comparison of the two theories.

Transactional model of stress.

Some level of stress is normal in parenting. All parents, regardless of disability status, worry about their children's well-being and future and their own abilities to meet their children's needs. However, certain life circumstances or problems may elevate stress beyond a normal level which then negatively influences parenting behavior. Disability may increase stress by increasing the difficulty parents have completing caregiving tasks and providing for their children's needs.

Although not developed to apply to parents with disabilities, the transactional model of stress contributes to understanding the possible mechanism through which disability might influence stress level. This model was introduced by Lazarus and Folkman in 1984 (Lazarus & Folkman, 1984). In this model, stress is a cognitive process that results from: (1) primary appraisal of an event as stressful or manageable, and (2) second appraisal of resources available to meet the demands of the event. Stress results when the perceived demands of the event exceed the perceived resources available. Figure 3.1 displays the theoretical relationship of parental disability to stress.

Figure 3.1
Relationship of disability to parenting stress



In this model, stress results from an assessment that the demands of parenting exceed the resources available to meet those demands (Deater-Deckard, 1998).

There are multiple reasons why parents with disabilities may experience more stress than non-disabled parents. First, the actual characteristics of the disability may result in greater demands being placed on the parent. Physical incapacity, poor emotional regulation or physical pain may make it harder for parents to relate to their children and care for their needs. Secondly, the results of the disability, such as reduced income, may create stress. Disability might also increase social isolation, in the case of mobility problems or fear of discrimination or stigma, leaving the parent alone to fulfill all the demands of parenting.

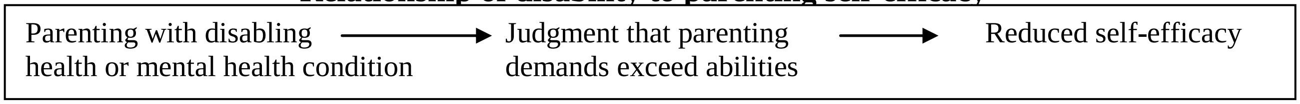
Excessive stress might lessen a parent's patience and care, resulting in either harsher, authoritarian parenting or indifferent parenting where rules and standards for behavior are not enforced. The bond between a parent and child may also weaken, as parents may be less likely to show affection to their children when they are caught up in stress and worry. Additionally, a "stressed out" parent may be less patient and able to discuss the child's misbehavior, instead reacting quickly, possibly even harshly. A key difference here might be that a parent under stress will be more likely to react to the child instead of interacting with him or her.

Baumrind theorizes that effective parenting includes both cognitive and affective responses. This elevated stress may limit parents' ability to relate to their children on both a cognitive and affective level. If a child is misbehaving, stress may prompt a parent to act out and physically punish the child. This can result in a weakened bond between the parent and the child, as the child begins to fear the parent, as well as a lost opportunity for the parent to use the misbehavior as a teachable moment. By reacting physically instead of cognitively to the misbehavior, the parent is modeling a lack of self-control and discipline to the child. Additionally, a parent experiencing stress from diverse sources such as financial insecurity and health limitations may be less likely to show affection to the child, as stress has been linked to reduced parental warmth (Deater-Deckard, 1998). Along with reduced warmth, elevated parenting stress has been associated with a lack of responsiveness, inconsistent discipline and unrealistic expectations for their children among non-disabled parent populations (Deater-Deckard, 1998; Gutermuth-Anthony et al, 2005; Pinderhughes, Dodge, Zelli, Bates & Pettit, 2000; Rodgers, 1998).

Self-efficacy theory. Self-efficacy, derived from Albert Bandura's writing on social learning, is defined as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (Bandura, 1994). While high self-efficacy motivates people to try new things, confident that they can succeed, low self-efficacy is associated with "weak commitment to the goals they choose to pursue" (Bandura, 1994).

Self-efficacy theory presumes that people's beliefs in their own abilities determine their actions. If someone has little faith in their ability to succeed in a particular task, they have little incentive to engage in that task. Figure 4 depicts the relation of disability to self-efficacy.

Figure 3.2
Relationship of disability to parenting self-efficacy



Bandura describes four sources of self-efficacy. The first is mastery. As parents successfully complete parenting tasks, they judge themselves to be competent parents. If, however, they fail on multiple occasions to meet their children's needs, they may begin to doubt their parenting ability, weakening self-efficacy. A second source of self-efficacy is modeling. The presence of strong, capable parents with disabilities serves as positive role models for other disabled parents. Thirdly, social persuasion may increase self-efficacy. If consistently told you can succeed, you will start to believe it. However, the opposite is also true. If, time and time again, you are told you will not succeed, that may reduce self-efficacy. In this way, stigma and discrimination may weaken self-efficacy. A parent who feels that social values disapprove of people with disabilities parenting may begin to question his/her own abilities as a parent (Wilson & Crowe, 2009). Finally, emotional responses to parenting tasks cue parents in to their own abilities. This connects self-efficacy to stress. Stress and tension may be seen as a "sign of vulnerability to poor performance" (Bandura, 1994). Parents experiencing high levels of stress may begin to doubt their parenting ability, as the completion of parenting tasks feels untenable. Strong social support may possibly negate this if the parent has the wherewithal to ask for assistance.

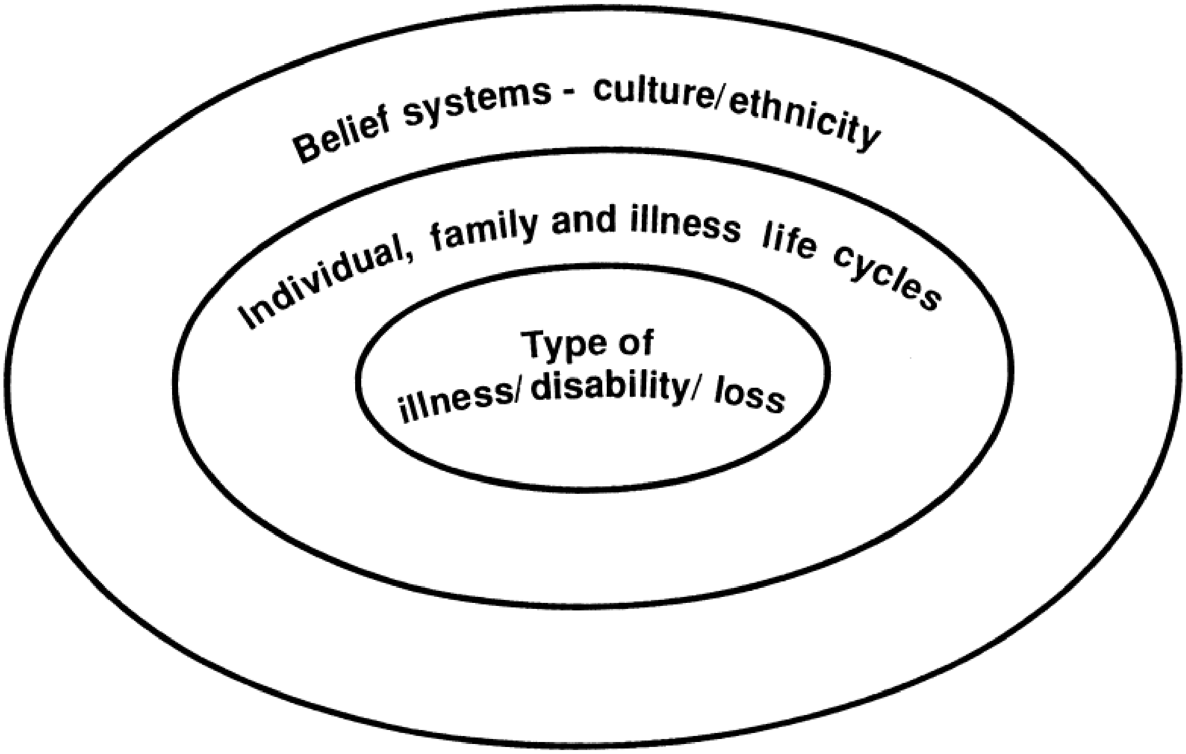
While both transactional stress and self-efficacy theories are cognitively based, self-efficacy theory gives greater weight to the internal psychological assessment process. Parenting self-efficacy is based on individual judgments of parenting ability over time. The transactional model of stress, on the other hand, is more dynamic, with stress levels changing over time in response to demands. This theory also places a greater emphasis on resources external to the parent, such as social support.

Empirical research on disabled families has considered how mental and physical disabilities affect parents' abilities to complete practical and emotive parenting tasks. When these tasks are not accomplished, it can have a negative impact not only on the healthy development of the child but on the psychological well-being of the parent. I turn next to Rolland's Family Systems-Illness model which considers characteristics that shape how parents and other family members understand and respond to disability and how this relates to the family life cycle.

The Dynamics of Disability and the Family Life Cycle

While the research presented above examined the relationship between a physical or mental health diagnosis and parenting processes, Rolland's Family Systems-Illness model teases out specific characteristics of disability that may shape parenting (Rolland, 1999). Disability is dynamic, and, like childrearing and household responsibilities, is fluid and changing over time. Rolland's model focuses on the "psychosocial demands" of the disability, not the diagnosis (Rolland, 2003, p. 464). Rolland's psychosocial categories include onset, course, outcome and incapacitation. Disabilities that have a gradual versus an acute onset are less likely to negatively impact parenting as families have more time to adjust to and brainstorm solutions to the parent's changing health status. Rolland defines three general courses diseases or disabilities can take: progressive, constant or relapsing. If the course is not constant, the parent must continually adapt to changing abilities and roles (Rolland, 2003, p. 465) which can result in exhaustion and diminished parenting effectiveness. The psychosocial impact of outcome is associated with the likelihood that the parent expects the disability to result in a shortened lifespan. Finally, degree of incapacitation is related to the extent, kind and timing of disability (Rolland, 2003, p. 466). As the disability progresses and changes, so does the family life cycle and the demands placed on a parent. A disability may become more or less incapacitating as the family's developmental needs change.

Figure 3.3
The Family Systems-Illness Model



Source: Rolland, J.S. (1999). Parental illness and disability: A family systems framework. *Journal of Family Therapy*, 21, p. 243.

Figure 3.3 depicts the relationship between disability, the family life cycle and the broader social and ethnic context of the family. How families understand and react to parental disability is a complex interplay of the characteristics of the disability, the needs of the family and the family's values and beliefs. The time phase of the disability, whether the symptoms are predictable or erratic, intersects with the family life cycle to influence the challenge presented by the parental disability at any moment in time. For instance, mobility limitations may be devastating to a family with an infant but have less impact for a family with a 17 year-old who has secured a driver's license.

Culture, race and ethnicity surround the family's reaction to parental disability. They influence the way families understand the cause of the disability, the symptoms and prognosis, who is the caregiver and who they believe should be the caregiver and their expectations of the outcome (Rolland, 2003). Religious values may also influence the ability of family members to accept the disability and prognosis and come to term with changes in family life.

This model has implications for work with parents with disabilities and their children. Social workers can help families develop a sense of mastery or control over the disability by addressing not just the physical complexities it creates but the psychosocial characteristics that may change relationships among family members. Conversation about the onset may help family members come to terms with the shock of a sudden change in family roles while sharing frustrations about the disruption of their day to day lives may prompt problem-solving. Assisting families to develop a shared belief system about the meaning of the disability and the future challenges it creates may promote adaptability and acceptance (Rolland, 1999). How families adapt to disability is a process that changes over time in relation to the complexities of family life.

Chapter 4: Methods

In chapter 2, I provided a definition of disability and reviewed the literature examining how disability may influence parenting and family well-being. In chapter 3, I presented theories of effective parenting and discussed how Rolland's Family System-Illness model can be a useful tool for understanding the role characteristics of disability play in family functioning. Building on this model, my study explores the specific relationship of disability to parenting practices and parent-child interaction. The literature review, discussion of effective parenting and Rolland's model became the basis for the survey I developed to answer my research questions.

This research builds on a previous study examining the well-being of SSI parents with children receiving TANF in San Francisco (Speiglman et al, 2010). Notable findings from the past study include significant material hardship, child health and behavioral problems and a high rate of involvement with child protective services among study respondents. This study contributes to existing knowledge by examining the relationship between disability and specific parenting practices, including expression of nurturance, involvement and parental control, as well as families' health and material well-being.

Procedures

Respondents are adult parents between the ages of 18 and 64 who have children under the age of 19 years and live in either San Francisco or Alameda County. All parents are disabled and have qualified for SSI, and their children currently receive or previously received CalWORKS cash aid. The types of disabilities possessed by the respondents are varied, including physical limitations, mental health problems and learning disabilities. All interviews were conducted in English. The subjects residing in San Francisco County participated in the 2010 SSI Parent Study (Speiglman, Mauldon & Sogar) and agreed to be recontacted for future research. The Alameda County respondents are new to the study and were randomly selected from the county's caseload of SSI parents with children receiving TANF. All respondents were mailed between 1 and 3 copies of a recruitment letter and consent form and asked to call if they were interested in participating in the study.

When respondents called in to participate, I reviewed the consent form (see Appendix A) with them and scheduled a time for the interview. Respondents were given a choice of a phone or an in-person interview. A total of 127 interviews were conducted between November 16, 2011 and October 22, 2012; 23 (18 percent) were done in-person. The majority of the in-person interviews were done at respondents' homes. Several were conducted at local coffee shops or restaurants and one was completed at a neighborhood elementary school. Interviews took on-average 55 minutes to complete, with a range from 30 minutes to 2.5 hours.

Following the interview, all respondents received a $40 grocery store gift card. At this time, respondents were invited to sign release of information forms which allow the Human Services Agency of San Francisco or the Alameda Social Services Agency to supply me with information about county-provided services, including Child Welfare services. Eighty-five respondents (67 percent) consented to the release of information. The administrative data will form the basis of a future study examining county supports for and Child Protective Services involvement among parents with disabilities.

Study Sample

All respondents in this study were parents of minor children who qualified for SSI on the basis of physical, mental health or learning disabilities. The majority of the respondents resided in Alameda County (77 percent) and the remainder lived in San Francisco County. Respondents were predominately African-American single mothers residing with one or two minor children. Forty-four percent lived with other adults, usually the respondent's adult children or other family members. The average length of time respondents had resided in their current county was over 25 years. Many had been residents of that county since childhood; that rate is over 65 percent in San Francisco and 51 percent for Alameda County respondents.

While 11 respondents (8.7 percent) were grandparents caring for their grandchildren, 13 respondents (10.2 percent) reported they had minor children not currently living with them, in addition to the children that lived with them. Of these 13 children, 1 was living with his other parent (father), 8 were living with other relatives, 1 had been adopted, 1 was in foster care, 1 was in juvenile hall and 1 was living at a residential treatment facility due to a behavior disorder. The mean age of these children not living with their mothers was 13.1 years with a median age of 16.5 years. Forty-two respondents (33 percent) live with other SSI recipients, most frequently their children with disabilities, occasionally their mothers or grandmothers.

Table 4.1
Descriptive data for study respondents

Demographics	**San Francisco County**	**Alameda County**	**All**
Gender			
Women	29 (100%)	91 (94%)	120 (95%)
Men	0	7 (6%)	7 (5%)
Mean Age	43.3 years	38.3 years	40.1 years
Race/ethnicity			
African-American	19 (65.2%)	63 (64.3%)	82 (64.6%)
Hispanic	3 (10.3%)	14 (14.3%)	17 (13.4%)
Native American	0	1 (1%)	1 (0.8%)
White	6 (20.7%)	12 (12.2%)	18 (14.2%)
Other/Multi-racial	1 (3.4%)	8 (8.2%)	9 (7%)
Mean Years Education	10.6 years	11.8 years	11.5 years
Mean Years Residing in Current County	31.6 years	24.7 years	26.2 years
Mean Age of All Minor Children Living with Respondent	13.6 years	10.5 years	11.1 years
Mean Age of Youngest Child	12.8 years	8.2 years	9.2 years
Mean Number Children in Household	1.5	1.8	1.8
Mean Years Receiving SSI	10.3 years	9.1 years	9.4 years
N	29	98	127

Measures

I developed a survey consisting of 8 sections to answer the 4 research questions laid out in the first chapter. The first section (Section A) collected demographic information, including gender, age, race/ethnicity and living situation. The second section (Section B) asked questions about the SSI application. Section C focused on respondents' health and mental health, including questions about the onset, course and expected outcome of the disability. Sections D and E measured parenting practices and parent well-being. The questions in Section F inquired about past involvement with Child Protective Services. The final two sections, G and H, asked about material hardship and access to county-provided resources and supports. Potential responses to all questions included "don't know" and "refused to answer" in addition to the response options listed below.

Dependent variables.

Dependent variables assessed parenting practices, including nurturance, involvement and family organization, and parent well-being, as well as prior or current involvement with Child Protective Services.

A. Caregiving.
    a. Caregiving limitations were assessed through the Parent Disability Index (see Appendix B for the full list of questions). Based on the age of the child, parents rate their difficulty completing between 15 and 21 parenting tasks. Answer choices range from of 0 (no difficulty) to 3 (unable to do); the parent's level of difficulty is defined as the mean of all scores. For parents of younger children (birth-5 years) the index measures the difficulty completing tasks such as dressing, picking up or playing with their children. For older children, parents report their difficulty "taking child all the places s/he needs to go" and "helping child with homework," along with other tasks.

B. Parenting dimensions. The Parenting Dimensions Inventory was utilized to assess 5 separate parenting constructs: nurturance, inconsistency, follow-through, family organization and parental control. Responses for the first three scales ranged from "Not at all like me" (1) to "Exactly like me" (6), with a higher score indicating a higher level of the construct being measured.
    a. Nurturance (6 items). "I encourage my child to talk about his/her problems." "My child and I have warm caring times together." "I encourage my child to be curious, to explore and to question things." "I find it interesting and educational to be with my child for long periods." "I make sure my child knows I appreciate what he/she tries to accomplish." "I respect my child's opinion and encourage him/her to express it."
    b. Inconsistency (4 items). "Sometimes it's so long between my child's bad behavior and when I can deal with it that I just let it go." "There are times I just don't have the energy to make my child behave as he/she should." "My child can often talk me into letting him/her off easier than I planned." "My child convinces me to change my mind after I have refused a request."
    c. Follow-through (3 items). "I always follow through on discipline for my child no matter how long it takes." "Once I decide how to deal with my child's

misbehavior, I follow through with it." "I believe that once a family rule has been made, it should be strictly enforced without exception."

    d. Family Organization (4 items). We have a regular dinner schedule each week." "Our house is clean and orderly." "Our family is organized." "We get everything done around the house that needs to be done." Answer choices were "1-never," "2-once in a while," "3-sometimes," "4-frequently," "5-most of the time," or "6-always."
    e. Parental control (5 items) (see Appendix C). For each item, parents were given a set of two statements and asked to choose which one they agreed with more. They received one point for each statement that indicated greater control, with total scores ranging from 0 to 5.

C. Parent well-being.
    a. Parenting stress was measured by the Parenting Stress Index Short Form, a 36-item questionnaire designed to identify potentially dysfunctional parent-child relationships. This index consists of 3 subscales that each contain 12 items: (1) Parental Distress, the stress parents feel in the parenting role; (2) Parent-Child Dysfunction, the extent to which parents are satisfied with their relationships with their children; and (3) Difficult Child, the parents' perception of their children's behaviors that make parenting more or less difficult. The scores for each item range from 1 (strongly disagree) to 5 (strongly agree) and are summed to create a total stress score, with a higher score indicating a greater amount of parenting stress.
    b. Parenting competence was measured by the 9-item Parent Sense of Competence Scale (see Appendix D). Satisfactory test-retest reliability (ranging between .46 and .82) has been reported for this scale (Johnston & Mash, 1989). Item B ("I meet my own personal expectations for expertise in caring for my child") was not used due to respondents' lack of understanding.

D. Child welfare involvement. "Has Child Welfare, Child Protective Services or the (name of county) Family and Children Division ever contacted you about your child/any of the children who live with you?"

Independent variables.

A. Pathways to SSI.
    a. Applied as child. "How old were you when you first started getting SSI?" Answer choices include ages 1 through 17 years.
    b. Applied as adult. "How old were you when you first started getting SSI?" Answer choices include ages 18 years or greater.
    c. Transition from TANF. "Did you receive TANF cash aid prior to SSI?"

B. Health status and incapacitation.
    a. Physical health limitations are measured by the number of limitations in Activities of Daily Living (ADL's) reported by the respondent (see Appendix E) as well as the number of household tasks respondents' reported needing help with (see Appendix F).
    b. Personal care limitations. "Do you need help with personal care, things like eating, bathing and brushing teeth?" Chronic pain is measured by 4 items from the Chronic Pain Grade Scale. "How bad is your pain right now?" "In the past 6 months, how intense was your worst pain?" "In the past 6 months,

on average, how bad has your pain been?" "In the past 6 months, how much has pain interfered with your daily life?" For the first 3 questions, answer choices range from 1 to 10, with 1 representing no pain and 10 representing the worst pain imaginable. For the last question, the response scale is also 1 through 10 with 1 representing no interference and 10 representing the inability to function. In the analyses that follow, Level of Pain refers to the average pain respondents' experienced in the prior 6 months.

  c. Global health scale. "How would you rate your health right now?" Responses were "excellent," "very good," "good," "fair" or "poor."
  d. Learning disability. "Do you have a learning disability that limits work?"
  e. Mental health. Symptoms of depression and anxiety were measured using 8 items from the Kessler Psychological Distress scale (see Appendix G).
  f. Post-Traumatic Stress Disorder (PTSD). PTSD was assessed through two separate methods. First, respondents were asked if they had ever been diagnosed as having PTSD by a doctor, nurse or other health professional. Secondly, respondents completed the 4-item PTSD scale (see Appendix H).

C. Characteristics of disability.
  a. Onset. "When you first began to experience problems with your health, did your health change suddenly, gradually or did your health change following an injury or trauma?" Responses include, "acute," "gradual," or "injury or trauma."
  b. Course. "In the last 30 days, has your health been about the same each day, or does it change from day to day?" Responses were "same" or "changing."
  c. Expected outcome. "Do you worry that your health problems will someday shorten your life?"

D. Demographic variables.
  a. Age. "How old are you?" Responses ranged from 22 to 69 years.
  b. Gender. "Are you female or male?"
  c. Race/Ethnicity. "What best describes you in terms of race/ethnicity?" Responses included "African-American or black," "Asian," "Hispanic or Latino," "Native American or Alaskan Native," "Native Hawaiian or other Pacific Islander," "White or Caucasian," or "Other."
  d. Living situation. "What kind of place are you living in now?" Responses included, "Room, apartment or house that you rent," "Apartment or house that you own," "In a friend or family member's room, apartment or house," "Hotel or motel," "Shelter for single adults or families," or "Somewhere else."
  e. Age of children. "How old was your child on his/her last birthday?" Responses ranged from 1 through 18 years. This question was asked for each of the respondents' minor children.
  f. Number of minor children. "How many babies or children under 19 years of age live with you?" Responses ranged from 1 through 5.

E. Health status of children. "Does your child/Do any of your children have any health condition, disability, learning, emotional or behavioral condition that limits the kind or number of things he/she/they can do, such as playing, going to school or participating in daily life or regular family activities?" If the response was yes, respondents were asked, “What health or emotional condition?” A “yes” was recoded to 1 for the indicator Child Health Problem, which otherwise took the value 0.

F. Housing assistance. “Is your rent reduced because the government or another agency pays for part through Section 8 or another housing subsidy program?”

G. Support. Both personal and professional sources of support were assessed.
   a. Professional. “Do you receive help through In-Home Supportive Services?” “
   b. Personal.
      i. Practical. “Thinking about the most important adult in your life in the last month. How much support does that person give you for doing the activities you need to do on a typical day, maybe helping with the children or with your health or with managing the house?” Responses included, “No support,” “A little support,” “Some support,” “A lot of support,” or “No one comes to mind.”
      ii. Emotional. Is there an adult is your life, a friend or a family member, who is an important emotional support for you, maybe someone you can talk to about your problems and count on to be there?
      iii. Economic. Two questions asked about economic support from friends or family members. “Is there an adult in your life who helps you financially, maybe lending you money on occasion?” In the analysis this measure is labeled Financial Support. “What about things other than money, like groceries or school supplies? Did anyone help you out last month by giving you things like that which you need?” In the analysis this measure is labeled Material Support

H. Experiences of material hardship.
   a. Inadequate housing. “During the last 12 months, were you ever homeless?” If respondents gave a positive response, they were asked more questions including, “Where did you stay when you were homeless” and “How many weeks were you homeless?”
   b. Hunger and other hardships. “In the past 12 months, how many times if any have you not had enough money to: pay your rent or mortgage; pay phone, gas, electricity, water or heat bills; buy the food your family needed; buy the things your children needed, like clothes and shoes?” Responses for each question ranged from 0 to 12. In the analysis, any number between 1 and 12 was recoded as 1. Respondents were also asked if they had received food from a church or food bank or meals from a soup kitchen or shelter in the past 12 months.

Human Subjects

This study was approved by the Committee for the Protection of Human Subjects (CPHS) at the University of California at Berkeley (protocol number 2011-06-3355). Memorandums of Understanding were created with both San Francisco and Alameda Counties detailing the data that would be collected and the analyses that would be performed.

Chapter 5: Results

Research question 1: What are the varying pathways through which parents with disabilities come to apply and qualify for SSI?

There are several different routes parents may take to SSI. First, they may qualify for SSI as children and continue to receive benefits as adults. As they would not have any work history, they would not be eligible for SSDI and would receive only SSI cash aid. Second, they may become disabled or aware of a disability as an adult and apply for SSI (or a combination of SSI and SSDI) due to limited work histories and income and resources. A final pathway to SSI (and possibly SSDI as well) is through other public assistance programs, namely TANF. In this study, nineteen respondents (15 percent) qualified for SSI before the age of 18 years. Of the 108 respondents that qualified for SSI as adults, the majority (77 percent) transitioned to SSI from TANF. Overall, the parents were approved for SSI at 30.9 years, on average, and had been receiving SSI for 9.4 years. Table 5.1 compares age at enrollment and years receiving SSI for all respondents, those who qualified as children, those who qualified as adults, and those who transitioned from TANF. Independent sample t-tests found the age difference between those parents who transitioned to SSI from TANF and those who qualified as adults without prior TANF receipt to be a statistically significant 4.6 years ($p<.05$). Both groups reported that their health problems began roughly 10 years before they were approved for SSI, equating to an average age of 26 years for those who qualified from TANF and 20 years for those without prior TANF receipt. This difference was also statistically significant ($p<.05$).

Table 5.1
Average age at SSI enrollment and years receiving SSI

Characteristic	**Mean value for all respondents (N=127)**	**Qualified as children (N=19)**	**Qualified for SSI as adults (N=108)**	**Qualified as adult w/o prior TANF receipt (N=25)**	**Transitioned from TANF (N=83)**
Average age at SSI enrollment	30.9 years	12.2 years	34.2 years	30.7 years	35.3 years
Average years receiving SSI	9.4 years	15.9 years	8.2 years	11.2 years	7.3 years
Average age health problems began	23.1 years	10.6 years	25.2 years	20.2 years	26.2 years

Table 5.2 details the reasons respondents reported applying for SSI. The percentages equate to greater than 100 percent due to some respondents providing multiple reasons for applying. For respondents that began receiving SSI as minors, over half (53 percent) qualified

on the basis of a learning disability. The majority of respondents gave specific physical and/or mental health diagnoses that limited their ability to work and prompted their decision to apply for SSI. One out of 10 respondents reported being victims of violence that left them with mental health problems, including Post-Traumatic Stress Disorder (PTSD).

Table 5.2
Reasons for SSI application

Reason for applying to SSI	All respondents	Qualified as children	Qualified as adult w/o prior TANF receipt	Transferred from TANF
Mood disorders	40 (32%)	2 (11%)	7 (28%)	31(37%)
Intellectual disability	15 (12%)	10 (53%)	3 (12%)	2 (2%)
Health problems/general disability	14 (11%)	3 (16%)	4 (16%)	7 (8%)
Victimization/PTSD	13 (10%)	1(5%)	2 (8%)	10 (12%)
Diseases of the:				
Muscoskeletal and connective tissue	10 (8%)	0	4(16%)	6 (7%)
Nervous system	6 (5%)	0	1(4%)	5(6%)
Circulatory system	5 (4%)	0	1 (4%)	4 (5%)
Respiratory system	4 (3%)	0	0	4 (5%)
Skin	4 (3%)	2 (11%)	0	2 (2%)
Blood and blood-forming organs	3 (2%)	1(5%)	1(4%)	1(1%)
Digestive system	1 (1%)	0	0	1(1%)
Injury (not resulting from assault)	8 (6%)	0	2 (8%)	6 (7%)
Unable to work	7 (6%)	0	2 (8%)	5 (6%)
Someone suggested it	6 (5%)	0	2(8%)	4 (5%)
Congenital anomalies	3 (2%)	1 (5%)	0	2 (2%)
Endocrine, nutritional and metabolic disease	3 (2%)	0	1 (4%)	2 (2%)
Schizophrenia	2 (2%)	0	2(8%)	0
N	127	19	25	83

Upon deciding to apply for SSI, applicants can choose to complete the application independently, ask friends or family members for help or turn to a professional source. According to the Social Security Administration, the tasks applicants frequently need help with include gathering and giving information, completing forms, transportation to medical appointments and representation at hearings and appeals (Social Security Administration, 2013). Various professional sources exist, including attorneys, doctors, and social workers. The professional source may negotiate a fee for service, however, it must be approved up-front by the SSA and is typically limited to 25 percent of back pay of benefits up to a maximum of $6,000.

For the respondents that qualified for SSI as adults, the majority did receive help with the SSI application[4]. Table 5.3 displays the frequency with which respondents who did or did not transition from TANF utilized different sources of application help. The respondents who did not previously receive TANF did not have TANF social workers available to them as a source of help with the SSI application. Respondents who previously received TANF were more likely to be helped by attorneys while respondents who did not previously receive TANF were more likely to turn to friends or relatives for assistance. Although parents did have the opportunity to report more than one type of application help, they were asked which source of help they relied on most throughout the application period. That is the source of help used for each parent in Table 5.3. Respondents who transitioned from TANF to SSI applied more times on average, waited longer to approval and felt the application process was more difficult than respondents who did not receive TANF prior to SSI. Independent-sample t-tests found the number of applications or appeals to be significantly different between those who transitioned to SSI from TANF and those who never received TANF.

Table 5.3
Source of help, number of applications, length of time to approval and difficulty rating by TANF status

	Transferred from TANF	**Qualified as adult w/o prior TANF receipt**
Source of help:		
Doctor	15 (18%)	6 (24%)
Attorney	20 (24%)	2 (8%)
Non-profit agency staff	13 (16%)	4 (16%)
TANF worker	6 (7%)	0
Friend/Relative	11 (13%)	7 (28%)
No help	18 (22%)	6 (24%)
Average number of applications/appeals	1.8	1.4**
Average length of time to approval	16.6 months	11.7 months
Felt application process was difficult	49%	40%
N	83	25

+p<.10, *p<.05, **p<.01

Comparing self-reported physical and mental health limitations between those who transitioned from TANF and those who did not found few differences. Respondents who transitioned from TANF to SSI reported greater psychological distress and ADL limitations, more health problems among their children and a lower rate of learning disabilities than respondents who did not previously receive TANF. Levels of support from family and friends were similar between groups. Overall, 29 percent of respondents reported that CPS had ever

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[4] These questions were not asked of respondents who qualified for SSI as children due to their limited recall of the application process.

contacted them about their children. This rate was even higher among those who transitioned from TANF (p<.01).

Table 5.4
Health, demographic and support characteristics and CPS involvement by TANF status

	Transferred from TANF	**Qualified w/o prior TANF receipt**
CPS ever contacted respondent about own children	36%	16%**
Work-limiting physical health problems	81%	75%
Work-limiting mental health problems	72%	61%
Work-limiting learning disability	33%	50%*
Acute onset or trauma/injury onset to disability	56%	47%
ADL limitations	2.1	1.9+
Psychological distress	21.7	19.0*
PTSD	52%	45%
Child health problem	47%	27%*
Number children	1.7	2.0+
Practical support from family or friends	64%	63%
Emotional support[a]	74%	72%
Financial support[b]	49%	37%
Material support[c]	35%	28%
Housing subsidy[d]	59%	45%+
Unable to pay rent	23%	20%
Unable to pay utilities	43%	57%+
Food insecurity	36%	43%
N	83	44

+p<.10, *p<.05, **p<.01

[a] Is there an adult in your life who helps you with the activities you need to do on a typical day, maybe helping with the children or with your health or with managing the house?
[b] Is there an adult in your life who lends you money on occasion?
[c] Did any friend or family member help you out last month by giving you things that you need like groceries, clothes or school supplies?

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[d] Is there an adult in your life who is an important emotional support for you, maybe someone you can talk to about your problems and count on to be there?

Research question 2: What are the major health, economic and caregiving needs and supports of SSI-parent families?

Parent health.

When asked, “What age were you when you began to first experience health problems,” parents answered 23.1 years on average. Considering their overall health on a scale from 1 through 5 with 1 as excellent and 5 as poor, parents on average rated their health as 3.7, between good and fair.

Figure 5.1 displays the types of work-limiting health problems reported by parents[5]. Seventy-eight percent of parents reported a physical disability; for 21 percent, that was their only health problem. Sixty-eight percent of parents reported mental health problems. Almost all had some other type of disabling health problems as well: only 9 percent had no other types of health problems. Thirty-nine percent of parents reported a learning disability; 7 percent experienced no accompanying physical or mental health problems. The majority of parents (63 percent) reported co-occurring health, mental health or learning disabilities. Thirty-nine percent reported health problems in 2 of the 3 categories and 24 percent reported problems in all three categories (physical, mental health and learning disabilities).

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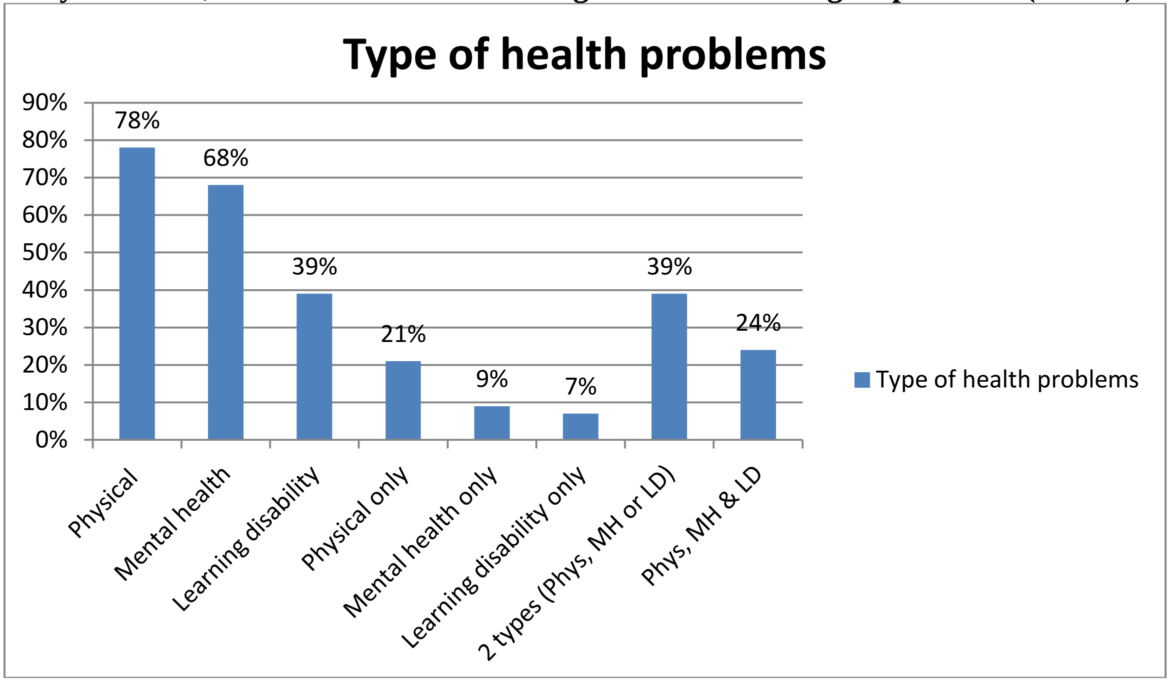
[5] This figure is referring to the same questions on work-limiting health problems that were broken down by TANF status in table 5.4.

Figure 5.1
Frequency of health, mental health and learning disabilities among respondents (N=127)



Four out of five respondents (81 percent) reported experiencing pain on a regular basis throughout the past 6 months. These parents answered 4 questions from the Chronic Pain Grade Scale scales from 1 through 10 with a higher score indicating greater pain or interference. The questions and their responses are shown in table 5.5. In the analysis that follows, "level of pain" refers to the average intensity of pain respondents' experienced in the previous 6 months.

Table 5.5
Chronic Pain Questions

PAIN	
How bad is your pain right now?	5.5
In the past 6 months, how intense was your worst pain?	9.2
In the past 6 months, on average, how intense was your pain?	6.5
In the past 6 months, how much has pain interfered with your daily life?	6.9

Parents were asked about the limitations in ADL's they experienced in the 30 days prior to the interview. Those results are shown in Table 5.6. Over half the parents reported limitations in 8 of the 11 activities.

Table 5.6
Frequency of ADL limitations

Activity	**% with specific limitation (N=127)**
Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports.	87%
Walking more than a mile.	79%
Moderate activities, such as changing a bed, pushing a vacuum cleaner, or carrying a small child.	72%
Lifting or carrying groceries.	71%
Climbing several flights of stairs.	70%
Climbing one flight of stairs.	64%
Walking several blocks.	63%
Bending, kneeling, or stooping.	62%
Walking one block.	45%
Using your hands for tasks like writing or typing.	45%
Bathing or dressing yourself.	38%

Respondents who reported limitations in ADL's were also more likely to report that pain interfered with activities, and greater intensity of pain. Scores on two of the pain measures, average pain intensity in the past six months, ("In the past 6 months, on average, how intense was your pain?") and interference from pain ("In the past 6 months, how much has pain interfered with your daily life?) correlated very strongly with activity limitations. The correlation coefficients are detailed in table 5.7.

Table 5.7
Correlation between pain and ADL limitations

	Correlation Coefficients	
Physical activity/Household task	**Pain intensity in past 6 months**	**Interference from pain**
Moderate activities, such as changing a bed, pushing a vacuum cleaner, or carrying a small child.	.34**	.47**
Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports.	.16+	.35**
Lifting or carrying groceries.	.23*	.25**
Climbing one flight of stairs.	.35**	.31**
Climbing several flights of stairs.	.32**	.29**
Bending, kneeling, or stooping.	.22*	.40**
Walking one block.	.32**	.26**
Walking several blocks.	.37**	.34**
Walking more than a mile.	.27**	.35**
Bathing or dressing yourself.	.37**	.38**
Using your hands for tasks like writing or typing.	.19*	.28**

+p<.10, *p<.05, **p<.01

Table 5.8 details the number of parents that reported needing help with various household tasks. Parents reported needing the most help carrying groceries, cleaning their homes and grocery shopping. While respondents needed help with a large number of activities, most 74 percent) reported they were receiving the help they needed. Of these respondents, 33 percent were helped by someone in their household, 21 percent by friends or family members not living in their household and 46 percent were helped by a paid caregiver, most frequently provided by In-Home Supportive Services.

Table 5.8
Need for help with household tasks

Task	**% reporting needing help**
Lifting or carrying groceries.	72%
Cleaning your apartment or house.	71%
Shopping for food.	65%
Doing laundry.	59%
Cooking for yourself or your child(ren).	50%
Getting up or down stairs.	39%
Writing checks, getting your rent paid on time, and taking care of your money.	35%
Bathing or dressing yourself.	31%
Taking medications when and how you're supposed to.	24%

Along with physical limitations, depression, stress, insomnia and worry appear to be widespread among respondents. When asked, "In the past 4 weeks, has depression or stress interfered with taking care of your kids, your home or other parts of daily life," 83 respondents (65 percent) responded positively. Respondents were also asked, "In the past 4 weeks, have other problems with your emotions or mental health, such as worry or insomnia, interfered with taking care of your kids, your home or other parts of daily life?" Again, the majority of respondents (63 percent) answered affirmatively.

Eight questions from the Kessler Psychological Distress scale were asked to assess mental health and well-being. Scores range from 8 through 40, with higher scores indicating greater psychological distress. The aggregate scores on the 8 items indicated a severe mental disorder for one out of 3 respondents (35 percent). There was a positive association between work-limiting mental health problems and respondents' scores on the Kessler scale (.36, p<.001).

Table 5.9
Frequency table of respondents' scores on the Kessler Psychological Distress Index

Score	
Under 16 = well	36 (29%)
16-19 = mild mental disorder	22 (18%)
20-23 = moderate mental disorder	24 (19%)
24+ = severe mental disorder	44 (35%)
N	126

Fifty-two respondents (41 percent) scored positively for Post-Traumatic Stress Disorder (PTSD) on the 4-question PTSD scale and 41 respondents (32 percent) reported a past diagnosis of PTSD; 27 (21 percent) both scored positively and reported a past diagnosis of PTSD. The correlation coefficient between the two sets of data is a statistically significant 0.35 ($p<.001$). Sixty-six respondents either scored positively on the PTSD scale or reported a past PTSD diagnosis. This equates to over half the sample (52 percent) that have experienced past trauma or victimization great enough to result in PTSD. PTSD scores correlated significantly (.449, $p<.001$) with respondents' scores on the Kessler Psychological Distress Index, indicating that ongoing mental problems go hand-in-hand with PTSD.

Child health.

On a global scale of 1 through 5 with 1 being excellent, most parents rated their children's health as excellent, very good or good. Only 18 parents (14 percent) rated their children's health as fair or poor. The average score of all parents was 2.2, between very good and good. However, the parents reported a high rate of health problems among their children. Fifty-two parents (41 percent) reported activity-limiting physical, emotional or behavioral problems among their children. The discrepancy may be that parents were answering the global health scale question considering their children's physical health and not their overall emotional and behavioral health.

Table 5.10
Frequency table of child health problems

	N
Congenital anomalies	1
Endocrine, nutritional and metabolic diseases	1
Autistic disorders	1
Mood disorders	10
Intellectual disability	6
Developmental disorders	10
Infectious diseases	1
Diseases of the:	
Nervous system	1
Blood and blood-forming organs	1
Respiratory system	27
Digestive system	4
Musculoskeletal system and connective tissue	2

By far, the most commonly reported conditions among children were diseases of the respiratory system, namely asthma. This was followed equally by mood disorders (usually depression) and developmental disorders.

Caregiving.

Respondents completed the index for caregiving limitations (“PDI”), which consists of two different scales measuring caregiving limitations. The first asked about caregiving tasks for children age 5 and younger and the second was for children between the ages of 6 and 18. Parents answered one or the other based on the age of their youngest child. Thirty-nine parents responded to the questions on the first scale and 85 parents answered the questions on the second scale. Data was missing for 3 respondents. The parents caring for younger children were asked about tasks in 21 domains. On average, they reported some level of difficulty completing tasks in 8.4 domains, 40 percent of the total. The parents caring for older children were asked about tasks in 15 domains. On average, they reported some level of difficulty completing tasks in 7.7 domains, 51 percent of the total.

The index for caregiving limitations (“PDI”) was calculated as the mean difficulty level across the domains of parenting described in Appendix B. Responses for each domain were scored to range from 1 to 3, with 1 representing no difficulty and 3 representing great difficulty in completing caregiving tasks. The mean score (averaged across 21 caregiving domains) for the cohort with younger children (39 parents) was1.59. Parents in the cohort with older children reported slightly more difficulty, with an average score of 1.79, averaged across 15 domains. Table 5.11 presents the average scores for each caregiving task for the cohort with older children, the cohort with younger children and the scores for all youngest children.

Table 5.11
Average scores on the index for caregiving limitations (“PDI”)

Caregiving Limitation with Oldest Child	**Average Score (Note: a higher score implies more problems)**		
Asked about youngest child of any age (0-17):	**Youngest child age 0-5**	**Youngest child age 6-17**	**All youngest children**
N	39	85	124
Mean Caregiver Limitations (“PDI”)[1]	1.59	1.79	1.73
Having the energy to talk/listen to your child.	1.59	1.73	1.69
Having the energy to be patient with your child.	1.74	1.86	1.82
Having other children in your home.	1.70	1.82	1.78
Getting up with your child.	1.59	1.65	1.63
Keeping your child out of unsafe situations.	1.21	1.31	1.27
Doing household chores or shopping.	2.10	2.27	2.22
Taking care of your child when he/she is sick.	1.33	1.45	1.41
Taking your child to social or recreation events.	1.95	2.11	2.06
Feed your child.	1.46	2.07	1.88

Playing with your child outdoors.	1.77	2.20	2.07
Maintaining discipline with your child.	1.54	1.60	1.58
Asked only if older child age 0-5 years:			
Dress your child.	1.46	--	
Take care of your child's hygiene (such as bathing or brushing teeth).	1.49	--	
Pick up or carry your child.	1.87	--	
Taking your child in/out of car.	1,75	--	
Getting up and down from floor to play.	2.00	--	
Using a stroller	1.18	--	
Using a car seat.	1.36	--	
Taking care of your child while out of the house.	1.67	--	
Opening safety latches or locks.	1.41	--	
Opening medicine or childproof containers.	1.44	--	
Asked only if older child age 6-18 years:			
Helping your child with homework, school functions.	--	1.76	
Taking your child to all the places s/he needs to go.	--	1.80	
Being involved in your child's school functions.	--	1.88	
Helping your child solve personal/social problems.	--	1.39	

1. Each respondent's Caregiver Limitations Score is the mean of all measures for which that individual provided data.

Regardless of the age of their children, parents reported the greatest difficulty doing household chores or shopping, playing with their children outdoors and taking their children to social or recreational events. Considering tasks specific to parents of younger children, parents reported the most difficulty getting up and down from the floor to play with their children. Parents of older children had the most difficulty being involved with their children's school functions. Parents of all ages reported the least difficulty keeping their children out of unsafe situations, taking care of their children when they are sick and maintaining discipline.

Respondents completed the Parenting Dimensions Inventory, which measures five subscales: Nurturance, Inconsistency, Follow-Through on Discipline, Organization and Amount of Control. For all scales, a higher score indicates a greater degree of the construct being measured. The first three subscales were answered by 118 respondents (9 missing data), the

Organization subscale was answered by 123 respondents (4 missing data), and the final subscale was answered by 109 respondents (18 missing data). Answer choices for the first 4 subscales ranged from 0 through 6; for the final scale, answer choices ranged from 0 through 5.

The Parent Sense of Competence (PSOC) scale measures the confidence parents feel in their own parenting styles and skills. The mean scores for each item are shown in Appendix E. The mean score overall for 126 respondents was 26.4, with an average item score of 3.3 indicating that in general respondents were neutral about the quality of their parenting (1 respondent missing data).

The Parent Stress Index was the final measure of parenting completed by the respondents. This scale yields a Total Stress score from three subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CD) and Difficult Child (DC). Answer choices for each item range from 1 ("strongly disagree") to 5 ("strongly agree") with a higher score on each subscale as well as the total index indicating greater stress. Each of the subscales consists of 12 items and thus has a maximum score of 60. One question in the Difficult Child subscale was not used in this study ("think carefully and count the number of things which your child does that bother you") due to respondents' difficulty in understanding and answering the question. That equates to a maximum score of 55 for the DC subscale in this study. The PSI Total Stress score is the sum of the scores on the three subscales. The mean scores for each scale are shown in table 5.12.

Table 5.12
Parenting Dimensions Inventory,
Parenting Stress and Parent Sense of Competence Scales

Parenting Construct	Mean Score	N
Nurturance	5.21	118
Inconsistency	2.92	118
Follow-through	4.34	118
Organization	4.48	123
Control	3.66	109
Parent Sense of Competence	26.40	126
Parent Stress Index Subscales:		
Parental Distress	34.70	126
Parent-Child Dysfunction	29.63	126
Difficult Child	31.48	126
Parent Stress Index (sum of the 3 subscales)	98.63	126

The Parental Distress subscale reflects the level of distress parents feel in their role as parent. The Parent-Child Dysfunction subscale indicates parents may have a negative perception of their interactions with their children and their children are not meeting their expectations. The Difficult Child subscale assesses parents' views of their children's temperament, defiance and noncompliance. High scores for each subscale at the total index are considered to be those at or above the 90th percentile of scores found in the general population (Adibin, 1995). The majority of respondents in this study scored high on the Parent-Child Dysfunction subscale as well as the total index. Table 5.13 details these findings. These scores indicate that many parents may benefit from professional assistance to help them combat the stress in their relationships with their children.

Table 5.13
Mean scores on the Parent Stress Index relative to the general population

	High Score (at or above the 90th percentile)	Mean score	% scoring at or above 90th percentile
Parental Distress	36	34.70	43%
Parent-Child Dysfunction	27	29.63	73%
Difficult Child	36	31.48	29%
Parent Stress Index (sum of the three scores)	90	95.80	65%

Overall, it appears that parents face severe health and mental health problems and physical limitations. Many parents did report problems completing basic caregiving tasks for their children and experienced a high level of parenting stress. On the positive side, however, most parents reported a high level of nurturance, family organization and follow-through with discipline.

Parenting processes and health and family characteristics.

This next section considers how demographic and health characteristics relate to caregiving limitations ("PDI"), parenting stress and sense of competence as well as other parenting constructs such as nurturance and follow-through. Bivariate analyses were used to discern the correlation coefficients of these parenting variables. Table 5.14 reports the covariates for caregiving limitations ("PDI"). There were statistically significant associations between the level of caregiving limitations reported by parents and average level of pain over the prior 6 months, psychological distress, and ADL limitations for both age cohorts. In all three cases, the associations were positive, with greater caregiving limitations reported among parents experiencing more pain, psychological distress or ALD limitations. Child health problems, coded as 1 if reported by parents or 0 if not, were also positively related to caregiving limitations and this association approached significance. When I tested the covariates for the combined age cohorts, the values were very similar and those are the values presented in table 5.14.

Table 5.14
Covariates for Caregiving Limitations ("PDI")

	Youngest Child Age 6-17	Youngest Child Age 0-5	Correlation coefficients for all respondents
Mean value of index	1.59	1.79	1.73
Age of parent	44.1 years	30.6 years	.197*
Level of pain	5.67	4.44	.352***
Psychological Distress	20.36	20.80	.476***
ADLs	1.87	2.16	.679***

Number of years on SSI	9.7 years	8.3 years	-.137
Parent learning disability	34%	48%	-.129
Number of children	1.8	1.7	.028
Age of Youngest Child	13.2 years	3.1 years	.297***
PTSD	51%	54%	.137
Child health problem	47%	31%	.176+

+p<.10, *p<.05, **p<.01, ***p<.001

The covariates for the Parent Dimension Inventory subscales are shown below. Again, bivariate analyses were run to calculate all correlation coefficients. These results indicate that characteristics of the parents are more strongly associated with parenting practices than child characteristics or the number of minor children in the household. Greater length of SSI receipt as well as the presence of a parental learning disability was associated with a lower-level of self-reported nurturance. Inconsistency was positively associated with parental psychological distress as well as PTSD. Greater psychological distress was also correlated with less household organization. Finally, older parents reported greater parental control, although PTSD was associated with less parental control.

Table 5.15
Covariates for Parenting Dimensions Inventory

	Parenting Construct				
	Nurturance	**Inconsistency**	**Follow-through**	**Organization**	**Control**
Mean score	5.21	2.92	4.34	4.48	3.66
Age of parent	-.117	-.055	.045	.019	.242**
Average pain prior 6 months	-.018	.004	-.022	-.123	.054
Psychological Distress	.041	.220**	-.047	-.226**	-.137
ADLs	.039	-.097	.019	-.052	.140
Number of years on SSI	-.329***	.081	-.104	.037	.028
Parent learning disability	-.269***	.126	-.037	.106	-.070
Number of children	-.037	.078	-.028	-.058	-.052
Age of youngest child	-.013	-.039	-.017	-.074	.140
PTSD	.095	.236**	.063	-.098	-.195**
Child health problem	.071	.146	-.052	-.037	-.041

*p<.10, **p<.05, ***p<.01

Table 5.16 presents the covariates for parenting stress and parenting sense of competence. Greater psychological distress was associated with more parenting stress and less parenting competence. PTSD and children's health problems increased parenting stress while decreasing competence. The age of the child was also negatively correlated with parenting competence, as parents of younger children reported a greater sense of competence.

Table 5.16
Covariates for the Parenting Stress and Parent Sense of Competence Scales

	PSI Subscales and Total Stress Score				
	Parental Distress	**Parent-Child Dysfunction**	**Difficult Child**	**Parenting Stress Index (sum of the 3 subscales)**	**Parenting sense of competence**
Mean score	34.69	27.82	31.06	83.31	26.4
Age of parent	.027	-.012	.066	.018	-.031
Average pain prior 6 months	.272***	.183*	.096	.281***	-.061
Psychological Distress	.634***	.347***	.305***	.622***	-.435***
ADLs	.173*	.057	-.163	.151	.098
Number of years on SSI	-.060	.041	-.081	-.032	-.063
Parent learning disability	-.044	.143	.018	.014	-.024
Number of children	.219**	.042	-.002	.174*	.135
Age of youngest child	-.109	.197**	.052	.054	-.227*
PTSD	.255***	.170*	.085	.279***	-.247**
Child health problem	.197**	.215**	.178*	.242**	-.248**

*p<.10, **p<.05, ***p<.01

I next examine the presence of private and public supports and their relationships with health, economic and caregiving characteristics.

Economic well-being and availability of supports.

Nine out of ten respondents live in their own homes or apartments that they rent. In San Francisco, all but 1 respondent (97 percent) live in their own rental housing. The corresponding percentage in Alameda is 88 percent. Of the 13 respondents that do not live in their own rental housing, 12 live with family or friends. One respondent was homeless at the time of the interview and living in a shelter with her child. Only 2 respondents, the mother living in the shelter and one parent living with a relative, did not report paying rent. The average rent reported by respondents was $568, although the average rent was quite a bit higher in Alameda County ($614) than San Francisco County ($451). This difference is directly related to the likelihood that the respondent has Section 8 or some other type of housing subsidy. While three out of four (76 percent) San Francisco county respondents had a housing subsidy, that rate was less than half among Alameda county respondents (47 percent). Overall, 54 percent of all respondents have a housing subsidy. Table 5.17 details the average rent and likelihood of experiencing material hardship among all respondents, those with housing subsidies and those without. Respondents were considered to have experienced each type of hardship if they reported that it occurred in one or more months of the previous year.

Table 5.17
Average rent and material hardship among respondents with and without housing assistance

	All (N=127)	With housing subsidy (N=68)	Without housing subsidy (N=59)
Average rent paid	$568	$390	$787
Unable to pay rent	22%	16%	29%
Unable to pay utilities	48%	44%	52%
Food insecurity	37%	38%	37%

Housing subsidies did protect against difficulty paying rent (p<.05), but rates of other types of hardship did not significantly differ between groups.

Child-only TANF aid is available to children whose parent(s) receive federal disability benefits, such as SSI, as well as to children of ineligible immigrant parents and those living with non-parental caregivers. Most (85 percent) respondents reported receiving child-only TANF averaging $347 per month for one child. This high rate of child-only TANF receipt is due to the sampling strategy utilized by this study. Respondents were randomly selected from county databases of families with SSI-receiving parents and children receiving TANF. Although theoretically all families should have reported child-only TANF income, 15 percent had their benefits suspended. Most of these parents stated they did not understand why the child-only TANF benefits had stopped. According to a county administrator, it was most likely due to incomplete paperwork. Recent research on the characteristics of child-only TANF cases estimates that over 70 percent of eligible SSI-receiving parents are not receiving child-only TANF benefits (Mauldon et al, 2012).

Material hardship appeared to be more common among respondents reporting mental health problems that limit work than among respondents without mental health problems. Although they were slightly more likely to report problems paying utilities, independent-sample t-tests reveal respondents with mental health problems were significantly more likely to report problems paying rent or providing adequate food for their families. Parents with mental health problems were also more likely to have received food from a food bank in the previous year than parents without mental health problems – 50 vs. 30 percent. While more likely to turn to a community support such as a food bank, parents with work-limiting mental health problems were less likely to report material contributions from family or friends. While 43 percent of respondents without work-limiting mental health problems reported receiving contributions such as groceries or clothes in the previous month, the corresponding percentage among respondents with mental health problems was 28 percent. This suggests that even if parents with physical disabilities have more trouble physically travelling to access public supports, they more often receive basic necessities from friends and family members. Levels of practical, financial and emotional support were similar between the two groups. Overall, the majority of parents, 3 out of 4, reported having adequate emotional support.

Table 5.18
Relationship of mental health problems to material hardship

	All (N=127)	With mental health problem (N=87)	Without mental health problem (N=40)
Average rent paid	$568	$605	$476
Unable to pay rent	22%	26%	13%*
Unable to pay utilities	48%	49%	45%
Food insecurity	37%	44%	25%*
Housing subsidy	54%	53%	55%
Received food from food bank in previous 12 months	44%	52%	30%*
IHSS	28%	25%	35%
Practical support	64%	63%	65%
Financial support	45%	44%	48%
Material support	32%	28%	43%*
Emotional support	74%	73%	75%

*p<.05

I next looked at the relationships between supports and needs. Those results are presented in Table 5.19. Considering private sources of support, parents who reported greater practical and emotional support from friends and family experienced less material hardship, measured as food insecurity, and having been unable at some time to pay for rent or utilities. Practical support was also negatively associated with parenting stress, indicating that having friends or family members available to help with household chores and childcare reduced the stress parents felt in their parenting role. However, the more activity limitations (measured in ADL's) or caregiving limitations that parents reported, the less financial and material support received from family or friends. It appears that people with more ADL limitations receive more public assistance in the form of housing subsidies and IHSS and perhaps as a result are less reliant on material support from family and friends. Age may likely moderate this relationship between public assistance and ADL limitations. It often takes many years to move to the top of a waiting list for a housing subsidy, so older parents are more likely to have finally reached the top of the list. ADL limitations are also associated with age, as older parents are more likely to report physical problems and receive IHSS assistance as a result. The correlation between ADL limitations and age was a statistically significant .23 (p<.01).

Table 5.19
Correlations between public and private supports and material hardship, health, caregiving and demographic characteristics

	Private Sources of Support				**Public Sources of Support**		
	Practical support (household help unpaid)	**Emotional support**	**Financial support**	**Material support**	**Housing Subsidy**	**Food bank**	**IHSS**
Material hardship:							
Inability to pay rent	-.198*	-.322***	.023	-.056	-.174+	.115	-.006
Inability to pay utilities	-.232**	-.182*	-.008	-.094	-.119	.119	-.081
Food insecurity	-.200*	-.110	.040	-.003	.001	.269**	-.210*
Health characteristics:							
ADLs	.032	-.129	-.185*	-.323***	.184*	.047	.515***
Psych. Distress	-.108	-.087	.156+	-.190*	.027	.199*	.037
Average Pain (past 6 months)	-.136	-.009	-.151+	-.272**	.046	.162	.260**
Child health problems	-.072	-.070	-.043	-.164+	.251**	-.025	-.064
Caregiving characteristics:							
Caregiving limitations (“PDI”)	-.021	-.109	-.107	-.307***	.237**	.058	.289**
Parent Stress Index	-.252**	-.137	-.015	-.178*	.050	.149	.006
Parenting Sense of Competence	.107	-.017	-.037	.097	-.115	-.071	.032
Nurturance	.047	.052	-.026	-.014	-.015	-.123	-.058
Inconsistency	-.191*	.013	.024	-.001	-.080	.175+	-.096
Follow-through	.037	.146	-.001	-.108	-.083	-.018	.068
Organization	.139	-.013	-.075	-.010	-.075	-.314***	.052
Control	-.025	.104	-.094	-.124	.221*	-.086	.173+
Demographic characteristics:							
Parent age	.057	-.040	-.193*	-.313***	.242**	-.077	.275**

Number of children	-.029	.069	.192*	.044	.105	-.043	-.013
Age of youngest child	.025	-.039	-.123	-.195*	.201*	-.019	.219*

+p<.10, *p<.05, **p<.01, ***p<.001

Research question 3: Within a sample of SSI-receiving parents, are particular characteristics of disability (e.g., onset, course, and worry about outcome) associated with parenting practices?

To examine this question, I first tabulated the responses to the questions measuring the disability characteristics (gradual versus acute or traumatic onset; stable versus changing course; and worrying or not that health problems will shorten their lives) The majority of parents (53 percent) experienced an acute or traumatic onset to their disability, face symptoms that vary from day to day (68 percent) and worry that their health problems will shorten their life (67 percent).

Table 5.20
Characteristics of disability - frequencies

Disability Characteristic	**%**
ONSET:	
Acute	24%
Gradual	47%
Injury/trauma	29%
Health Stability in Past 30 Days:	
Stable	32%
Changing	68%
WORRY ABOUT OUTCOME: Worry that health problems will shorten life	
Yes	67%
No	33%

Parents were asked what types of activities they have trouble completing some days but not others. The most common response, given by 44 percent of respondents, was “get out of bed.” Responses are listed in Table 5.21. Percentages equate to more than 100 due to some respondents reporting problems completing multiple activities.

Table 5.21
Activities frequently limited

Activity	**%**
Get out of bed	44%
Household chores	25%
Walk/exercise	23%
Take care of children	15%
Leave the house	12%

Bathe/ toilet/ get dressed	9%
Prepare meals	7%
Talk/ deal with people	6%
Know what's going on/ remember things	6%
Have patience and cope	4%
Eat	4%

Hospitalizations and emergency room use were asked as another measure of instability of health status. Seventeen respondents (13 percent) reported overnight hospitalization in the prior 3 months. Respondents who were hospitalized were admitted an average of 1.5 times for an average of 4.2 nights. Forty-seven respondents (37 percent) visited an emergency room in the prior 3 months due to a problem with their health. Of the respondents that did visit an emergency room, 19 went one time, 24 went two or three times, two respondents went to an E.R. between 4 and 10 times, and 2 went 11 or more times in the prior 3 months. These two measures were significantly correlated (.39, p<.01), indicating those respondents who were hospitalized were also more likely to be treated at an emergency room.

Table 5.22
Relationship of disability characteristics to health, demographic and parenting characteristics

	Onset		**Health Stability in past 30 days**		**Worry that health problems will shorten life?**	
	Acute/ Injury/ Trauma	**Gradual**	**Changing**	**Stable**	**Yes**	**No**
N	67	60	86	41	85	42
Age of parent	42.7 years	37.3 years**	41.4 years	37.3 years*	40.8 years	38.8 years
Average pain prior 6 months	5.6	4.9	6.8	5.3**	6.6	6.8
Psychological distress	20.8	20.6	22.6	16.8***	22.4	17.1***
ADLs	2.1	2.0	2.0	2.1	2.2	1.8***
Number of years on SSI	8.8 years	9.9 years	9.6 years	8.9 years	8.9 years	10.3 years
Parent Learning Disability	31.3%	46.7%*	32.3%	51.2%*	30.6 %	54.8%**
Number of children	1.8	1.8	1.8	1.8	1.8	1.7
Age of youngest child	10.2 years	8.1 years*	9.6 years	8.4 years	9.9 years	7.7 years*
PTSD	59.7%	38.4%**	52.3%	43.9%	51.8	45.2%

					%	
Child health problem	43.3%	38.3%	44.2%	34.1%	44.7%	33.3%
Caregiving limitations (“PDI”)	1.8	1.7	1.8	1.5***	1.8	1.5***
Nurturance	5.3	5.1	5.3	5.1	5.2	5.1
Inconsistency	3.0	2.8	3.0	2.8	3.0	2.7
Follow-through	4.2	4.6+	4.4	4.3	4.4	4.3
Organization	4.3	4.5	4.3	4.7*	4.4	4.5
Control	3.6	3.8	3.8	3.5	3.5	4.0*
Parenting sense of competence	25.6	26.4	25.9	26.3	25.4	27.2+
Parent Stress Index	96.0	93.9	98.9	86.9***	95.0	95.2

+p<.10, *p<.05, **p<.01, ***p<.001

Table 5.20 details the results of independent sample t-tests comparing the means of health and demographic variables and parenting constructs by disability characteristics: gradual versus acute or traumatic onset; stable versus changing course; and worrying or not that health problems will shorten their lives. The age of the parent was related to onset and course, as those with a gradual onset and stable course were younger than parents who experienced an acute or traumatic onset or changing course. Considering health characteristics, parents with a stable course reported experiencing less pain on average over the past 6 months than parents who symptoms were more varied. Parents with a stable course that did not worry about health problems shortening their lives also experienced less psychological distress although they were more likely to report a learning disability.

Caregiving limitations were found to be significantly different for respondents based on course and outcome characteristics. Those respondents with a stable course and those who did not worry that their health problems would shorten their lives reported fewer limitations in caregiving as measured by the PDI scale. Parents with a gradual onset were more likely to follow-through with discipline. Parents with a stable course also experienced less parenting stress than respondents with more varied symptoms.

Linear regression was employed to test if these relationships held when other potentially explanatory variables were introduced. The multivariate models are displayed in table 5.23 through 5.26. The first set of models (presented in tables 5.23 and 5.24) considered the relationship of health (psychological distress, PTSD, ADLs and child health problems) and demographic (age of parent, age of youngest child, number of children) variables to parenting constructs. These models were most predictive of caregiving limitations, parenting stress and sense of competence and inconsistency. Controlling for other variables, caregiving limitations were found to vary as a result of psychological distress, ADL limitations and the age of the youngest child. All of these associations were positive. Parenting sense of competence was negatively associated with psychological distress and age of the youngest child, implying that parents with greater levels of psychological distress and older children felt less competent. Parenting stress was found to be related to psychological distress and children's health problems. Finally, inconsistency varied as a result of PTSD.

The second set of models included the age of the parent and number of children as well as the disability characteristics of onset, course, and worry about outcome. These models are presented in tables 5.25 and 5.26. As with the first set of models, the second set were most predictive of caregiving limitations and parenting stress. Caregiving limitations were related to level of pain experienced over the prior 6 months and parenting stress was associated with the stability of the course. Parents who experienced more varied symptoms reported more parenting stress. Although these models were not predictive of parenting sense of competence or inconsistency, model 16 in table 5.26 did explain significant variation in the level of parent control. This was found to be mainly related to the age of the parent, with older parents expressing greater control. Overall, it appears that parents' health and mental health status are more strongly associated with parenting process than the type of onset experienced, the stability of symptoms of the extent to which parents worry that their health problems will shorten their lives.

Table 5.23
Multivariate models of Parenting Limitations, Competence and Stress

	OLS Linear Regression Models					
	Model 1		**Model 2**		**Model 3**	
Covariates	**Caregiving Limitations**		**Parenting Competence**		**Parenting Stress**	
	Coeff.	Sig.	Coeff.	Sig.	Coeff.	Sig.
Age of parent	-.006		.030		-.237	
Number of children	.006		-.921	+	.774	
Age of youngest child	.015	*	-.264	*	.195	
Child health problem	.065		-1.397		9.414	*
ADLs	.474	***	-.196		-.733	
Psychological Distress	.016	***	-.224	**	.766	**
PTSD	.009		-.443		2.648	
F-Statistic	20.71		4.30		3.86	
N	122		125		125	

+ p<0.1 * p<0.05 ** p<0.01 *** p<0.001

Table 5.24
Multivariate Models of Parenting Dimensions Subscales

	OLS Linear Regression Models									
	Model 4		**Model 5**		**Model 6**		**Model 7**		**Model 8**	
	Nurturance		**Inconsistency**		**Follow-through**		**Organization**		**Control**	
	Coeff.	Sig.	Coeff.	Sig.	Coeff.	Sig.	Coeff.	Sig.	Coeff.	Sig.
Age of parent	.015		-.009		.010		.008	+	.024	
Number of children	-.065		.069		-.234		-.099		-.008	
Age of youngest child	-.226		.009		-.014		-.028		.005	
Child health problem	.192		.436		-.092		-.063		-.321	
Average ADLs	.057		-.359		.061		.065		.296	
Kessler Psychological Distress	-.013		.026		-.014		-.029		-.015	
PTSD	.225		.643	*	.207		-.230		-.379	
F-Statistic	.74		2.23		.22		1.37		2.00	
N	117		117		117		123		107	

Table 5.25
Multivariate Models of Parenting Limitations, Competence and Stress, as predicted by disability-specific measures

	OLS Linear Regression Models					
	Model 9		**Model 10**		**Model 11**	
Covariates	**Caregiving Limitations**		**Parenting Competence**		**Parenting Stress**	
	Coeff.	Sig.	Coeff.	Sig.	Coeff.	Sig.
Age of parent	.004		-.075		-.073	
Number of children	-.016		-.514		1.763	
Average pain prior 6 months	.064	**	-.181		1.231	
Acute onset (reference=Gradual)	.034		-1.030		1.404	
Unstable Course (reference=Stable)	.050		.088		14.957	**
Worry/Shorten Life (reference= Not)	.149		-1.851		.221	
F-Statistic	2.90		.96		2.63	
N	102		105		105	

+ p<0.1 * p<0.05 ** p<0.01 *** p<0.001

Table 5.26
Multivariate Models of Parenting Dimensions Subscales, as predicted by disability-specific measures

	OLS Linear Regression Models									
	Model 12		**Model 13**		**Model 14**		**Model 15**		**Model 16**	
	Nurturance		**Inconsistency**		**Follow-through**		**Organization**		**Control**	
Age of parent	.004		-.017		.009		.005		.036	**
Number of children	-.056		.041		-.027		-.067		-.079	
Average pain prior 6 months	-.053		-.039		.015		-.056		.030	
Acute onset (reference=Gradual)	.097		.349		-.460		-.195		-.446	+
Unstable Course (reference=Stable)	.317		.556		-.459		-.426		.049	
Worry/Shorten Life (reference= Not)	.062		.484		-.150		.258		-.526	+
F-Statistic	.54		.97		.79		.98		2.30	
N	97		97		97		103		92	

Research Question 4: Do families with prior child welfare involvement differ from parents without past child welfare involvement on measures of health, material well-being or parenting?

Overall, 29 percent of respondents reported that CPS had ever contacted them about their children. Among groups, independent sample t-tests found that respondents who experienced an acute onset to their disability or injury or trauma were significantly more likely to report CPS involvement than those who experienced a gradual onset ($p<.05$). While 36 percent of respondents who experienced an acute onset or injury or trauma reported past CPS contact, the corresponding percentage among respondents with a gradual onset to their disability was 22 percent.

Figure 5.2
Relationship of disability characteristics to CPS involvement

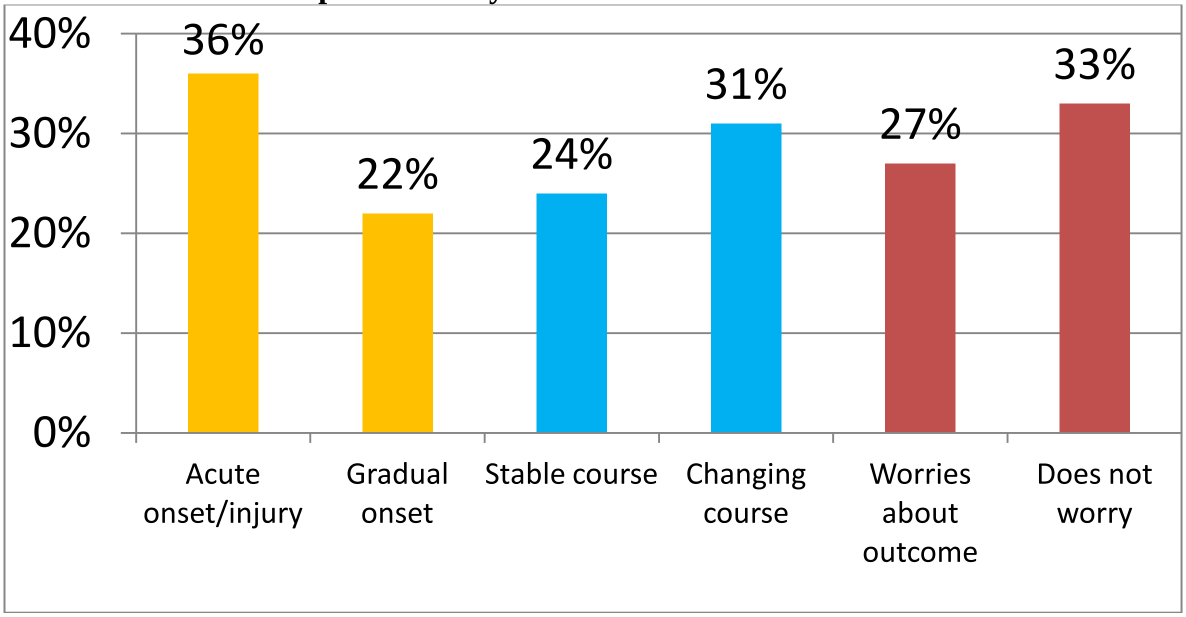


Table 5.27 examines the covariates of CPS involvement. Several relationships were found. Regarding parenting constructs, CPS involvement was associated with greater inconsistency and lower parental sense of competence. Having a housing subsidy or a child with health problems were both positively correlated with past or current CPS involvement ($p<.05$). Finally, parents with learning disabilities were less likely to report that CPS had ever contacted them about their children.

Table 5.27
CPS Covariates

	CPS involvement
Parenting construct:	
Caregiving limitations ("PDI")	.051
Nurturance	.056
Inconsistency	.178*
Follow-through	-.024
Family organization	-.092
Parental control	.031
Parenting Sense of Competence	-.212*
Parenting stress	.121
Material hardship:	
Inability to pay rent	-.050
Inability to pay utilities	.036
Food insecurity	.019
Health problems:	
Level of pain	-.071
Psychological Distress	.083
ADLs	-.066
Parent Learning disability	-.188*
Child health problem	.179*
Demographic characteristics:	
Age of parent	.003
Number of children	-.004
Age of youngest child	.142
Public and private supports:	
Practical support	-.094
Emotional support	-.004
Financial support	-.091
Material support	-.035
Housing subsidy	.157*
Food bank	-.034
IHSS	-.082

+p<.10, *p<.05, **p<.01

A series of logistic regressions examined predictors of CPS involvement. The first model utilized health and demographic variables. The second incorporated characteristics of disability. The third considered the relationship of parenting constructs to CPS involvement and the final model examined the role of public and private supports.

Table 5.28

Multivariate model of CPS involvement as predicted by demographic and health characteristics

	Logistic Regression Model 1	
Covariates	**CPS**	
	Odds Ratio	**Sig.**
Age of parent	.969	
Number of children	.931	
Age of youngest child	1.099	+
Child health problem	1.952	
ADLs	.556	
Psychological Distress	1.039	
PTSD	.719	
N	125	

+ p<0.1 * p<0.05 ** p<0.01 *** p<0.001

Table 5.29

Multivariate model of CPS involvement as predicted by disability characteristics

	Logistic Regression Model 2	
Covariates	**CPS**	
	Odds Ratio	**Sig.**
Age of parent	.987	
Number of children	.974	
Average pain prior 6 months	.937	
Acute onset (reference=Gradual)	.886	
Unstable Course (reference=Stable)	1.135	
Worry/Shorten Life (reference= Not)	.886	
N	105	

+ p<0.1 * p<0.05 ** p<0.01 *** p<0.001

Table 5.30

Multivariate model of CPS involvement as predicted by parenting constructs

	Logistic Regression Model 3	
Covariates	**CPS**	
	Odds Ratio	**Sig.**
Age of parent	.985	
Number of children	.826	
Caregiving limitations (“PDI”)	.981	
Parenting sense of competence	.958	
Parent stress	1.011	

Nurturance	1.127	
Inconsistency	1.408	+
Follow-through	1.262	
Organization	1.079	
Control	1.111	
N	99	

+ p<0.1 * p<0.05 ** p<0.01 *** p<0.001

Table 5.31

Multivariate model of CPS involvement as predicted by public and private supports

	Logistic Regression Model 4	
Covariates	**CPS**	
	Odds Ratio	**Sig.**
Age of parent	.989	
Number of children	.993	
Practical support	.605	
Emotional support	.766	
Financial support	1.054	
Material support	.905	
Housing subsidy	2.455	*
Food Bank	.696	
IHSS	.643	
N	119	

+ p<0.1 * p<0.05 ** p<0.01 *** p<0.001

The results of the logistic regressions are presented in terms of odd ratios. An odds ratio close to 1.0 indicates that the variables in of minor importance in determining the likelihood of CPS involvement. An odds ratio over 1.0 indicates the variable has a positive association with CPS involvement and below 1.0 indicates a negative association. The significance level shows the possibility that the association occurred by chance.

Overall, the models demonstrate very little predictive value. As can be seen in model 4, the housing subsidy variable emerged as the most important in predicting CPS involvement. Holding other supports constant, the odds of having had CPS contact are nearly 2.5 times higher for a parent with a housing subsidy than one without.

Chapter 6: Discussion and Conclusions

Summary of Results

Drawing on 11 months of field research with 127 SSI-receiving parents, this study examined the relationship between disability, economic hardship and parenting practices. It also explored the likelihood of families' involvement with Child Welfare Services. The first research question investigated the pathways through which parents apply for and receive SSI benefits. The second question considered the main health, economic and caregiving needs of SSI-parent families. After learning about the needs of parents, the next question looked at the relationship of disability characteristics to parenting and caregiving. The final question investigated whether families' health, economic and caregiving hardships differed by past involvement with child welfare services. The major findings revealed in this study are:

1. Parents who transitioned from TANF to SSI applied more times on average than those without prior TANF receipt and were more likely to report past CPS involvement.
2. Economic hardship was widespread; private supports from friends and family appeared to protect against financial need more than public sources of aid.
3. Controlling for health and demographic variables, disability characteristics (onset, course, and worry about outcome) explained little of the variation in parenting processes.
4. A history of CPS contact is correlated with greater parental inconsistency, a lower parental sense of competence and the presence of child health problems. It is also associated with having a housing subsidy. The causal processes that lead to these correlations are unknown. A parent found to be neglecting her child might have been given priority for a housing subsidy. In multivariate models the presence of child health problems was no longer significantly associated with a history of CPS contact although the odds ratio is large. When parental inconsistency and low sense of competence are together in a model, only the former is marginally significant.

While the health limitations reported by parents who received TANF prior to SSI were similar to those who did not, the age each group began to receive SSI was different as were rates of child welfare involvement.

Parents who begin to receive SSI as adults may or may not first receive cash aid from the TANF program. Comparing characteristics of those who did and did not receive TANF prior to SSI revealed few health-related differences between the groups. Rates of self-reported physical, mental health and learning disabilities were similar. Respondents who transferred from TANF to SSI were more likely than those without prior TANF receipt to report an acute or traumatic onset to their disability, but this difference was not statistically significant. The lack of a statistically significant finding may be due to the small sample size, however.

Parents without prior TANF receipt were younger than past TANF recipients when their health problems began and younger at SSI enrollment. These parents were in their early 20's on average when their health problems started while the parents with past TANF receipt were in their early 30's. Parents who struggle in the labor market due to disability may first turn to TANF for support. Facing time limits, they then apply for SSI. As parents who did and did not transition to SSI from TANF had similar health limitations, it is likely that parents who transitioned to SSI from TANF were older simply because their path included a failed labor market, time-limited TANF and then SSI.

SSI parents with and without prior TANF receipt differed in their reports of past child welfare involvement. While over one-third of parents previously on TANF were involved with child welfare services in the past, less than one-fifth of SSI parents that did not transition from TANF had CPS involvement. This suggests there is a relationship between TANF and Child Protective Services. It is possible that TANF social workers identify caregiving needs of TANF-receiving parents and refer them to child welfare. Past research on the topic, however, does not indicate TANF workers as common reporting sources for child maltreatment (Courtney et al, 2005). Rather, this finding is more likely related to the parents' and children's health status as parents with prior TANF receipt reported greater psychological distress and health problems among their children.

Greater public and private support only partially protected families against economic and caregiving problems.

While the majority of parents reported adequate practical and emotional support, they were less likely to report receiving financial or material help from friends or family. The most common public support reported by parents were housing subsidies followed by IHSS. Private supports appeared to offer greater protection against economic needs; both practical and emotional support correlated with less trouble paying rent or utilities or providing food. Of the public supports assessed in this study, housing subsidies correlated only with rent and IHSS with food insecurity. These findings partially support my hypothesis that public and private supports would protect against all types of economic hardship.

Respondents with more material support also reported fewer ADLs, less psychological distress and less pain, and were marginally less likely to report child health problems. Whether this correlation is because respondents with less physical and emotional need could engage in reciprocal relationships, both giving and receiving support, or whether the receipt of support alleviated their pain and distress, is not known. Practical supports from friends and family members were associated with less parenting stress and inconsistency. Material contributions were also linked to less parenting stress as well as caregiving limitations. Support did not correlate with other parenting constructs, including nurturance, follow-through and parenting sense of competence.

Housing subsidies and IHSS benefits were also associated with caregiving limitations, although the direction of effect was opposite that hypothesized. Housing subsidies and IHSS receipt correlated with greater caregiving limitations. Although the finding regarding housing subsidies is not clear, IHSS is meant to assist individuals with physical and self-care limitations. As an IHSS worker is only able to assist the parent with the disability and not her child, the same physical limitations that qualified the parent for IHSS may weaken her caregiving abilities.

Some aspects of parental disability were associated with caregiving and parenting constructs.

I hypothesized that psychosocial characteristics of disability, including onset, course and the worry about outcome, would be associated with parenting constructs. Specifically, I theorized that parents who experienced a gradual onset, whose symptoms were stable, who understood and accepted their current health status and who did not worry that their disabilities would shorten their lives would show greater nurturance and consistency toward their children, report greater parental control, sense of competence and family organization and experience fewer caregiving limitations and less parental stress. Individual sample t-tests found 5 of the measured parenting constructs to be associated with these disability characteristics. Instability in the presentation of symptoms was related to greater caregiving limitations, less organization and greater parenting stress. Worry about the outcome of the disability was associated with greater limitations in caregiving and less control. These results were not substantiated in linear regression analyses, however. While 4 of the 5 models did explain a significant amount of the variation found in the parenting construct, this was related to the parents' ongoing health and mental health. Greater psychological distress was associated with more caregiving limitations, lower parenting competence and greater stress. Control varied by PTSD status. It appears that constructs of control, consistency, parenting competency, caregiving limitations and parenting stress are reduced by pain, psychological distress, unstable health in the past month, acute rather than gradual onset and uncertainty about prognosis.

A history of past child welfare involvement is not associated with material hardship or parent psychological distress but rather is related to the children's health characteristics and the availability of housing subsidies.

Somewhat surprising, based on the other findings, is the lack of relationship between the parents' psychological distress and CPS involvement. Regression analysis indicated that housing subsidies were a better predictor of a family's CPS involvement than psychological distress or economic insecurity. It is plausible that parents who were investigated for child neglect were subsequently connected to housing assistance. Other studies have found a relationship between maternal mental health and CPS involvement, but that relationship was not detected in this study.

Discussion

While this study revealed a high degree of economic and health problems among SSI-receiving parents, strengths were also identified. Parents reported a high degree of parenting stress; however, they also expressed warmth, consistency in parenting and follow-through with discipline.

Disability is very complex and many of the parents reported co-occurring physical, mental health and/or learning disabilities. Results indicate considerable mental health needs among parents in this study. The scores of over one-third of respondents on the Kessler Psychological Distress Index indicate the presence of a severe mental disorder. These scores correlated highly with PTSD.

Economic hardship was most commonly reported by respondents with mental health problems. This finding appeared to be related to a greater degree of social isolation among parents with mental health problems. Parents with mental health problems turned to community supports such as food banks more frequently than parents without mental health problems, but this did not appear to provide adequate protection against hunger for many families.

The level of psychological distress as indicated by the Kessler Scale correlated significantly with caregiving limitations, inconsistency, lack of organization, greater parenting stress and lower parenting competence. While physical disability correlated positively with limitations in physical caregiving tasks, it was not related to the other parenting constructs assessed in this study.

In sum, this research suggests a different level of need among SSI-parents with mental health problems than among those without a mental health disability. SSI recipients qualify for

Medicaid and theoretically should have access to mental health services. Most research indicates that Medicaid recipients have, in the past, had adequate access to mental health services (Coughlin, Long & Kendall, 2002; Henry et al, 2011; Roll et al, 2013). However, there is some indication that there is growing unmet need due to states' budget crises. With the headline "State Mental Health Cuts Hit Low-Income People Hard," the article in the Huffington Post decries a loss of inpatient beds and reduction in community-provided services for low-income individuals with mental illness (Lippman, 2012). Cuts in mental health programs lead to longer waits for care and less consistency in appointment scheduling. As the Affordable Care Act goes into effect next year and Medicaid coverage is expanded, it is imperative that states, including California, invest in strengthening provision of mental health services to ensure needs are met.

Limitations

A main limitation of this study is the sample size. With a sample size of 127, the extent to which findings may be generalized to a broader population is limited. Additionally, all interviews were conducted with parents residing in two Northern California counties. The public supports utilized by many of these parents (housing subsidies, IHSS and food banks) are likely not as readily available in other areas of the United States and, thus, the circumstances of the mothers in this study are likely not representative of the broader population of low-income mothers with disabilities.

All findings were based on respondent self-report. For the parents that applied for and began to receive SSI many years ago, the accuracy of their reports regarding the application experience may be questionable. The results also may be subject to response bias, as parents may have chosen to not share the full extent of their caregiving limitations and problems parenting in order to appear to be strong caregivers. There is also the possibility of self-selection bias. Although individuals who received invitations to participate in the research were randomly selected, those who chose to take part may differ from those that did not.

Finally, the study measured parents' well-being and approaches to parenting at one point in time. As the symptoms of disability and parenting demands are dynamic, surveying respondents on a different day may have resulted in different findings. For many respondents, the needs of their children and the health symptoms they experience change on a daily basis. While one day they may feel overwhelmed by their parenting role, the next they may feel more in control and respond differently to survey questions. A longitudinal design would address this limitation.

Future Research

The first research question in this study looked at pathways to SSI. I identified differences between adults who received TANF prior to SSI and those who did not. Prior TANF recipients were older when approved for SSI and older when their health problems started. Those who received TANF first also had a different experience of the SSI application process, applying more times on average than those who did not transition from TANF. Future research ought to explore these differences in depth, including health and mental health diagnoses. It would be interesting to follow a group of TANF recipients over time and chart changes in mental health status, including depression and anxiety. By looking at mental health status over time for those TANF recipients who do and do not eventually apply for SSI, we could learn if the potential stressors of the TANF program, including time limits and work requirements, generate or aggravate health conditions in some recipients that prompt their SSI applications.

Secondly, I looked at the general well-being of SSI-parent families. As mentioned previously, disability and parenting are dynamic. To get an accurate understanding of the relationship of disability to caregiving limitations, surveys should be administered at multiple points in time. This research incorporated Rolland's characteristics of disability, including onset, course and worry about outcome. These variables affect not just the parent but other family members and the family as a whole. It would be interesting to assess children's views of parental disability, especially regarding the course of the symptoms. This would give a fuller picture of the role of parental disability in the family and how that changes over the course of the family life cycle.

There is a need for future research to examine the treatment of and outcomes associated with parents with disabilities in the child welfare system as limited data are currently available. In this study, parents who reported past contact with child welfare workers did not feel their disability was part of the conversation. The parents felt this was a good thing as they feared discrimination but it may have prevented the family from being connected to helpful services. It is important to learn more about child welfare workers' views of parental disability and potentially develop trainings to help child welfare workers and supervisors become more aware of and sensitive to parental disability. Also, more information is badly needed on prevalence, on what percentage of parents involved with child welfare have disabilities and what public and private supports they find most helpful and supportive of parenting.

Implications for practice

This descriptive study of the well-being of SSI-receiving parents found a link between poor mental health, problematic parenting and economic hardship. This research offers a first look at the ways disability shapes parenting in the context of limited income. Findings indicate the need for supportive services for SSI-receiving parents who qualified for SSI on the basis of a mental health diagnosis. There are several pathways through which these services could be delivered. One option is through CPS. There is stigma associated with CPS involvement, however, and families may be reluctant to engage in services. A second option is through disability services. A leading agency in providing services to parents with disabilities is Through the Looking Glass (TLG) in Berkeley, California. TLG provides direct services to parents with disabilities. Many of the direct services are aimed at helping adults with disabilities become parents and providing them with adaptive baby care equipment once they have children. Parents with mental health problems may face many of the same challenges as parents with physical disabilities, such as pain and fatigue, but their circumstances are also unique. Psychological distress and depression may interfere with the dyadic relationship that is required in parenting, disrupting the interaction between the parent and child. These needs suggest a service model that is focused on empowering the family as a whole.

I propose a family support model, funded by Title IV-B (Promoting Safe and Stable Families) funds, that provides greater services for parents with mental health problems than those currently offered by TLG. Based on the findings of this study, parents with mental health problems would benefit from help with physical caregiving tasks, including household chores and organization, methods for consistent discipline and a stronger connection to the community. The development of a peer network, where parents can share their strengths and struggles and feel supported in their parenting role, may serve to reduce the social isolation of parents with mental health problems.

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Appendix

Appendix A: Informed Consent Form

INFORMED CONSENT FORM FOR STUDY PARTICIPANTS
SSI Parent Study

Introduction

My name is Christina Sogar. I am a graduate student at the University of California, Berkeley in the School of Social Welfare, working with my faculty advisor, Professor Jane Mauldon in the School of Public Policy. We are planning to conduct a research study, which I invite you to take part in.

Purpose

The purpose of this study is to learn more about the needs and well-being of parents in the SSI program in San Francisco.

Procedure

If you agree to be in this study, we will interview you over the phone or in-person if you prefer. The interview will last approximately 45 minutes. We will ask questions about your background, family and living situation, housing, hunger and other hardships, physical and mental health and your children's health. We will also ask about how you view yourself as a parent and how you parent your children, including what methods of discipline you use. Finally, we will ask about past involvement with child welfare services

If you agree to participate, we will also ask your permission to receive information kept by the City and County of San Francisco about your family's receipt of child welfare and other social services. When we ask the City and County of San Francisco for information it has about you, we will give them only your name. We will not tell them anything that you have told us during the interview.

Benefits

Although the study may not benefit you directly, we expect the results will help design programs and target resources to assist parents receiving SSI and their children.

Risks

Some of the questions are of a personal nature. They might make you embarrassed or feel uncomfortable. If there are specific questions in the interview that upset you, you do not have to answer them, and we will go on to other questions. You may also take a break or stop the interview at any time. There is also a slight chance that information you give us would be seen by other people by mistake. Please see the confidentiality section below for more information.

Confidentiality

If results of this study are published and presented, individual names and other personally identifiable information will not be used. We will not discuss your answers and comments with anyone outside the research team. We will use an ID number for your interview so that your name is not used. We will keep the consent form and other material with your name in a locked cabinet, separate from your interview answers.

When the research is completed, I may save the interview notes for use in future research. I will retain this study information for up to 5 years after the study is over. The same measures described above will be taken to protect confidentiality.

Compensation

To thank you for your time, a researcher will bring you a $40 Safeway gift card after the interview. If the interview is done in person, you will receive the gift card at the conclusion of the interview.

Voluntary nature of research

- Rights

Taking part in this study is entirely voluntary. Your decision about whether to participate will not affect your eligibility for public assistance of any kind or other benefits to which you are otherwise entitled.

Questions

If you have any questions or concerns about your rights and treatment as a research subject, you may contact the office of UC Berkeley's Committee for the Protection of Human Subjects, at 510-642-7461 or subjects@berkeley.edu.

Do you have any questions now about the study or your involvement in it?

Consent to Participate

Let me read you a summary statement about this consent form. At the end I will ask you to tell me if you agree to participate in the study.

> *I have been informed about the SSI study and what is involved in participating. I voluntarily agree to participate. I can end the interview or withdraw from the study at any time. My participation is not connected with receipt of, or eligibility for, public benefits or assistance of any kind, for me or family members. My answers will be used only for research purposes and no publications resulting from this research will identify me by name. The researchers have provided me with a copy of this form.*
> *If you agree to be interviewed, please sign below.*

______________________________	______________________________
Signature of Study Participant	Date
______________________________	______________________________
Name of Study Participant	Date
______________________________	
Interviewer signature	

Appendix B: Parent Disability Index

	FOR OLDEST CHILD – IF AGES 0 to 5 YEARS:	Limited a Lot 1	Limited a Little 2	Did Not Limit 3	Refused -7
a.	Dress your child.				
b.	Take care of your child's hygiene (such as bathing or brushing teeth).				
c.	Feed your child.				
d.	Pick up or carry your child.				
e.	Taking care of your child while out of the house.				
f.	Taking your child in/out of car.				
g.	Getting up and down from floor to play.				
h.	Getting up with your child.				
i.	Keeping your child out of unsafe situations.				
j.	Playing with your child outdoors.				
k.	Having other children in your home.				
l.	Taking your child to social or recreation events.				
m.	Taking care of your child when he/she is sick.				
n.	Maintaining discipline with your child.				
o.	Having the energy to be patient with your child.				
p.	Having the energy to talk/listen to your child.				
q.	Doing household chores or shopping.				
r.	Using a stroller				
s.	Using a car seat.				
t.	Opening safety latches or locks.				
u.	Opening medicine or childproof containers.				

	FOR OLDEST CHILD AGES 6-18 YEARS	Limited a Lot 1	Limited a Little 2	Did Not Limit 3	Refused -7
a.	Taking your child to all the places s/he needs to go.				
b.	Being involved in your child's school functions.				
c.	Helping your child with homework, school functions.				
d.	Playing with your child outdoors.				
e.	Having other children in your home.				
f.	Going with your child to social events or recreational activities.				
g.	Getting up with your child at night/early morning.				
h.	Taking care of child when s/he is sick.				
i.	Keeping your child out of unsafe situations.				
j.	Maintaining discipline with your child.				
k.	Cooking or preparing meals.				
l.	Doing household chores or shopping.				
m.	Having the energy to be patient with your child.				
n.	Having the energy to talk/listen to your child.				
o.	Helping your child solve personal/social problems.				

APPENDIX C: Parenting Dimensions Inventory, Parent Control Subscale

1. Nowadays parents place too much emphasis on obedience in their children.
2. Nowadays parents are too concerned about letting children do what they want.

3. Children need more freedom to make up their own minds about things than they seem to get today.
4. Children need more guidance from their parents than they seem to get today.

5. I care more than most parents I know about having my child obey me.
6. I care less than most parents I know about having my child obey me.

7. I try to prevent my child from making mistakes by setting rules for his/her own good.
8. I try to provide freedom for my child to make mistakes and to learn from them.

9. If children are given too many rules, they will grow up to be unhappy adults.
10. It is important to set and enforce rules for children to grow up to be happy adults.

APPENDIX D: Parent Sense of Competence Scale

Parent Sense of Competence Scale	**Mean Score**
I believe I have the skills necessary to be a good parent to my child.	4.46
I meet my own personal expectations for expertise in caring for my child.	Not measured
If anyone can find the answer to what is troubling my child, I am the one.	3.98
Being a parent is manageable, and my problems are easily solved.	3.17
Sometimes I feel I am not getting anything done.	2.60 (reverse coded)
Being a parent makes me tense and anxious.	3.14 (reverse coded)
Even though being a parent is rewarding, I am frustrated now while my child is at his/her current age.	2.83 (reverse coded)
Sometimes when I’m supposed to be in control, I feel more like the one being manipulated.	2.74 (reverse coded)
I go to bed the same way I wake up in the morning – feeling I have not accomplished a whole lot.	3.29 (reverse coded)

APPENDIX E: Activities of Daily Living (ADLs)

Moderate activities, such as changing a bed, pushing a vacuum cleaner, or carrying a small child.
Vigorous activities, such as running, lifting heavy objects, or participating in strenuous sports.
Lifting or carrying groceries.
Climbing one flight of stairs.
Climbing several flights of stairs.
Bending, kneeling, or stooping.
Walking one block.
Walking several blocks.
Walking more than a mile.
Bathing or dressing yourself.
Using your hands for tasks like writing or typing.

APPENDIX F: Need for help with household tasks

Cleaning your apartment or house.
Lifting or carrying groceries.
Getting up or down stairs.
Bathing or dressing yourself.
Cooking for yourself or your child(ren).
Shopping for food.
Writing checks, getting your rent paid on time, and taking care of your money.
Doing laundry.
Taking medications when and how you’re supposed to.

APPENDIX G: Kessler Psychological Distress Index

a. Did you feel tired out for no good reason?
b. Did you feel nervous?
c. Did you feel hopeless?
d. Did you feel restless or fidgety?
e. Did you feel depressed?
f. Did you feel that everything was an effort?
g. Did you feel so sad that nothing could cheer you up?
h. Did you feel worthless?

APPENDIX H: Post-Traumatic Stress Disorder

In your life, have you ever had any experience that was so frightening, horrible, or upsetting that, <u>in the past four weeks</u>, you

a. Have had nightmares about it or thought about it when you did not want to?
b. Tried hard not to think about it or went out of your way to avoid situations that reminded you of it?
c. Were constantly on guard, watchful, or easily startled?
d. Felt numb or detached from others, activities, or your surroundings?