

A Historical and Current Analysis of Programs and Policies Affecting the Well-Being of Parents with Disabilities

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Abstract

This paper has a dual focus: to elucidate the meaning of disability over time as well as to examine the current situation of parents with disabilities and how they and their families are faring. First, within a historical context, I argue that our understanding of and policy response to disability is fluid and shifting. Who we consider disabled and the extent of their limitations is in large part a social construction based on the availability of income and other support services, and this has changed over time. Secondly, I synthesize the research on the well-being of low-income parents with disabilities and their children. This review of the literature increases our understanding of what it is like to parent with a severe mental or physical disability on a daily basis and allows for recommendations of specific services and supports that will best meet the needs of parents with disabilities and their families.

Keywords: Disability, policies, services, parenting, mental health

“My two-year old son watched me rolling around on the floor and screaming. I knew I was scaring him, but everything hurt so bad I just couldn’t regain control of my body or my emotions.” This quote comes from the mother of a two-year old who suffers from bipolar disorder and anxiety. Upon learning that her apartment was being sold and she would have to move, she suffered an emotional breakdown in the presence of her son. Although she feared for his well-being and safety, her psychiatric symptoms prevented her from comforting her son as she was trapped in her own anguish and despair.

Parents with disabilities face diverse daily struggles, from mental health problems that limit their ability to navigate stressful situations to physical problems that restrict mobility and strength. In detailing the research on parents with disabilities, this paper has a dual focus: to elucidate the meaning of disability over time as well as to examine the current situation of parents with disabilities and how they and their families are faring. First, within a historical context, I argue that our understanding of and policy response to disability is fluid and shifting. Who we consider disabled and the extent of their limitations is in large part a social construction based on the availability of income and other support services, and this has changed over time.

Secondly, I synthesize the research on the well-being of low-income parents with disabilities and their children. This review of the literature increases our understanding of what it is like to parent with a severe mental or physical disability on a daily basis and allows for recommendations of specific services and supports that will best meet the needs of parents with disabilities and their families.

1. 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 support 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 historical context in which it occurs.

This section of the article 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?

1.1 The Role of Civil Rights

Throughout the 19th century and the beginning of the 20th, “disabled” referred mainly to those who could not safely live in the communities 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 people were unable to support themselves, had 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 feeble-minded and promiscuous. Both had born children out of wedlock. Although less than one year old, Carrie’s daughter was also judged to be feeble-minded (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.

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

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. This act bans discrimination against people with disabilities 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.

1.2 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 was 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 that 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 the 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 somebody 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, in her book *Disabled State*, 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 ("Supplemental Security Income," 2016).

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," 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 self-inflicted nature of their disability makes them ineligible for aid. In this case, it is apparent that it is not the symptoms of the disability but the cause that provokes the response.

1.3 Changes Affecting Parenting

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 adults with disabilities are capable of and policy increasing access to income supports and housing. With greater community participation and less discrimination, more adults with disabilities 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 parents with disabilities 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.

The income assistance provided by SSI and SSDI may actually serve to motivate low-income parents to seek a diagnosis of their disabling conditions, thereby increasing the official number of parents with disabilities (Stone, 1984). If they are low-income parents, gaining eligibility for income support from SSI replaces the possibility of support from Temporary Aid for Needy Families (TANF), a cash assistance program for low-income parents. The two programs differ substantially. Most notably, SSI provides greater monthly payments without work requirements or time limits on aid.

Where TANF is funded as a block grant to the states, SSI is a federal income supplement program funded by general task revenues to provide monthly income for the blind or disabled who have little or no income. As of 2016, the federal SSI payment is \$733 per month for an individual. Most states provide a small supplement to the federal payment.

Both public perception and policy changes have created more opportunities for adults with disabilities to have and care for children. However, this does not necessarily mean that there are more parents with disabilities now than in past generations. Changes 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 1 details factors increasing or decreasing the likelihood of parenting with a disability.

Figure 1

Factors influencing the probability of parenting with a disability in the 21st century	
Increased:	Income support programs
	Financial incentives for diagnosis of disability
	Medical and technological advancements increasing independence
	Greater social acceptance
	In-home care services
	Anti-discrimination legislation
Decreased:	Improved working conditions and safety legislation
	Better medical treatment preventing disability after injury or illness
	Better management of chronic conditions

2. Parenting With A Disability

This next section reviews the literature on parenting with a disability. Research with parents suffering from diverse disabilities, including chronic pain, physical disability and mental health limitations, is explored to understand how parents respond to the social, material and personal challenges associated with disability.

2.1 Stigma, Stress and Self-Esteem

Evans and colleagues (2005) examined the relationship of stress and depression to chronic pain and found that mothers experiencing chronic pain reported significantly more symptoms of depression and stress and a decreased ability to complete parenting tasks. This was mediated by reduced psychosocial functioning which interfered with the mothers' abilities to complete basic caregiving responsibilities. The authors found a greater degree of conflict in the families of the chronic pain patients. They theorize that this conflict is a two-way process; "not only is the mother likely to impact on those around her, but also the amount of hostility and conflict displayed by family members may impact negatively on her functioning" (Evans et al, 2005, p. 688-689.) The authors conclude that the mothers' chronic pain cause psychosocial distress, which further limits their ability to care for their children and adds to family dysfunction, namely conflict between family members. This research indicates that the mothers' inability to adequately care for their children hurts not just the children but also the mother, causing emotional distress. The mothers' psychological state then makes it difficult for them to emotionally care for their children, further disrupting the relationship. The researchers found an association between the psychological symptoms of stress and depression and parenting efficacy.

These findings indicate that the relationship between chronic pain and inadequate parenting is mediated by mental health problems, namely depression and stress (Evans et al, 2005).

A 2008 study by Mazur looked at the impact of parental disability on family functioning. Parents with physical disabilities and their adolescent children were asked about the frequency of disability-related events in the previous month, including asking the child to get something out of reach of the parent, length of time to complete household task, and lack of ability to prepare a meal. Of the 19 parents that completed the survey, the most commonly reported negative events included the length of time to complete a household or parenting task, the inability to prepare a meal and not being able to participate in a physical activity with his/her child. The researchers found that these events were “consistently related to weaker feelings of parenting self-efficacy, lower adolescent self-esteem, more adolescent externalizing behaviors and greater parent and adolescent stress and depression” (Mazur, 2008, p. 532). Parents felt highly stressed about not being able to physically play with their children or complete household tasks in a timely manner. Furthermore, these limitations prompted them to judge themselves to be deficient parents.

A focus group of mothers who had been diagnosed with bipolar disorder revealed some common themes in their parenting experiences (Wilson & Crowe, 2009). They reported that emotional outbursts negatively impacted their relationships with their children, leading to stress, guilt and a sense of incompetence as a parent. As with physical disabilities, it is possible that disability and stress form a self-perpetuating cycle. The mental health problems result in more emotional outbursts, increasing the mother’s stress and weakening their parenting skills, which in turn exacerbate mental health symptoms. The mothers also reported stigma associated with their diagnosis. They felt they had to keep their mental health problems a secret or they would be prematurely judged as bad parents. Fear of stigma and discrimination caused these parents to assume that they had to struggle on their own or risk losing their children, further elevating stress. This sense of stigma potentially leads to reduced parenting confidence and self-efficacy, as parents question their own ability to meet their children’s needs.

A study examining the academic outcomes of children whose mothers’ had a mental illness found lack of parenting confidence mediated the relationship (Oyserman et al, 2005). Data was collected from 317 mothers with a diagnosed serious mental illness 3 times over a 22 month period. Mothers completed 4 questionnaires including psychiatric diagnosis, psychiatric function, functioning hassles and parenting practices. The psychiatric function scale measured engagement in household tasks while function hassles measured the stress invoked by those daily tasks (i.e. cooking or cleaning). The parenting practices scale assessed parenting style with questions that operationalized Baumrind’s typologies (authoritarian, authoritative, permissive). Finally, data was collected on children’s academic outcomes through school records and teacher reports of classroom behavior. While maternal mental health outcomes were found to be associated with worse academic outcomes, this relationship was confounded by lack of parenting self-efficacy. This lack of confidence resulted in permissive parenting, a lack of firm demands and rules placed on the child.

A 2008 study examined the impact of symptomology and parenting (Kahng et al, 2008). The researchers tested the hypothesis that when the symptoms of mentally ill parents declined, their nurturing behaviors would increase. Results showed that the relationship between psychiatric symptoms and parenting behaviors was mediated by stress level. Data revealed that “mothers with initially higher levels of symptoms also reported higher levels of parenting stress and lower levels of nurturance and that decline in symptoms was associated with reduction in parenting stress and increase in nurturance over time” (Kahng et al, 2008, p. 165). Bethany, who suffers from severe mental health issues, feels that she cannot effectively parent when she is in a stressful situation. When she found out that she would have to move, she binged on junk food, leaving her physically sick. She knew her two-year old son was scared by her illness but she felt too sick and helpless to go to him.

The study by Kahng and colleagues is significant in that it shows the ability of mentally ill parents to strengthen parenting abilities with a decline in symptoms. Furthermore, the impact of symptoms on parenting was mediated by stress. The amount of support the parent had in completing daily tasks in large part determined his/her stress level. These findings have implication for the type of resources and programs that may improve the ability of mentally ill parents to keep custody of and provide solid care for their children.

2.2 Intersection with poverty

A theme from the research presented above is that stress and low-self efficacy combine with poverty to disrupt parenting. Lack of resources amplifies the limitations created by the disability and the stress experienced by the parent. 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 parents with disabilities face greater economic challenges than parents without disabilities, it is important to consider the impact of poverty on parenting. For poor women with disabilities, what impact does this demonstrated material hardship have on their ability to parent? Of course, the lack of material resources will directly impact children, as it will be difficult if not impossible for their mothers to meet their physical needs. It also indirectly affects children's well-being through the stress and worry it creates for the mother. Parish and colleagues (2008) conducted focus groups with low-income mothers with disabilities to gain insight into how the intersection of disability and poverty impacts parenting.

Of the 35 women involved in the focus group, the majority were physically disabled (51.4%). Approximately one-third (31.4%) had a mental illness with the remainder (17.1%) experiencing intellectual disabilities. The number of children the women had ranged from 1 to 6 and the average age of the children was 14 years. The bulk of the mothers were Latina (48%) or African-American (40%). Several main themes emerged from the focus group conversations.

First, the women's lives consisted of a patchwork of interwoven challenges and hardships. From struggling to pay the bills to keeping their children safe, the women faced a multitude of complexities. The women in the focus group reported that these challenges changed over time, as eligibility for benefits varied and children encountered different physical, academic or social troubles. "For many of the women...the only constant in their lives was a seeming succession of multiple hardships" (Parish et al, 2008, p. 59).

Second, the focus group participants had concerns specific to being a parent with a disability. As can be expected, medical care was of high value to these participants. The women expressed concern that earning income would cause them to lose not just their cash assistance but Medicaid. Without Medicaid, none of the women would be able to afford their prescription medication. That made the potential risk of work outweigh the benefits of additional income for all focus group participants.

Finally, regardless of type of disability, depression is a significant problem among this population. This has been confirmed by past studies. For example, in 2002, Harrison and colleagues found disability to be an independent predictor of depression among mothers with varying degrees of impairment due to multiple sclerosis (Harrison et al, 2002). The women in the focus group study also expressed depression about their inability to provide for their children as a result of both their disabilities and poverty (Parish et al, 2008). Comments from the participants frequently linked depression to lack of social support and a sense of being overburdened by their responsibilities.

2.3 How Context Matters

Like many parents, parents with disabilities encounter a number of challenges to effective parenting. To what extent do these challenges result specifically from the parent's disability and how much are they a product of the context in which they occur? The literature review demonstrate the complex and interconnected effects social support, self-esteem and poverty have on parenting. Among single mothers with a mental health and/or physical disability, greater isolation and stress are related to increased material hardship. A lack of social support may also increase parenting difficulties as parents who receive little respite from their parenting role may be more likely to ignore their children's needs at times or respond with anger or frustration.

Recommendations to increase services and supports for parents with disabilities and their children are focused on strengthening caregiving supports, improving self-esteem and increasing the availability of material resources. First, respite care has been found to be associated with positive changes in family quality of life measures. In order to ensure that parents with disabilities who seek respite care are able to access it, a special category of Early Head Start and Head Start vouchers could be created for the children of parents with disabilities. By prioritizing this program for children of low-income parents with disabilities, the children would receive quality early education and the parents would have time to tend to their own needs, perhaps giving them greater energy to effectively parent when their children return home.

To address material needs, a proportion of Section 8 vouchers could be prioritized for parents with disabilities. All parents, but especially parents with disabilities, need access to safe, affordable housing. Imagine a parent with an anxiety disorder who can only afford housing in a violent, high-crime neighborhood. Being surrounded by drugs and guns would not do anything to quell their anxiety or strengthen their parenting. Greater access to Section 8 vouchers would allow parents with disabilities more freedom in choosing affordable housing in an area they are comfortable with.

In order to enhance the social support available to and self-esteem of parents with disabilities, communities may sponsor support groups for parents with disabilities. In these groups, parents can share successes and commiserate on problems. Most importantly, the groups would let members know they are not alone and hopefully reduce their perception of stigma related to disability. Likewise, school social workers could receive training to compassionately and effectively support parents with disabilities and their children, helping parents to feel supported by the school in their efforts to teach and care for their children.

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 people 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 parents without disabilities, frequently in the form of food insecurity (Parish et al, 2009). 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. It is possible that stress and disability become a self-perpetuating cycle. Parents with physical and mental disabilities may be less able to complete parenting tasks which increases their stress levels, their physical and/or mental symptoms and further threatens effective parenting.

Interventions are needed to break this cycle and improve parents' self-esteem, level of social support and material well-being. To achieve these goals, recommendations include improving the ability of parents with disabilities to access quality early education programs and affordable housing, creating peer groups to foster mutual support and resilience and building communication between parents with disabilities and their children's schools. These recommendations aim to strengthen the connection between parents with disabilities and their communities, improving family well-being over the long term.

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