

The Cost of Disability Advocacy: Adjusting the Self-Sufficiency Standard for Children with Disabilities

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Abstract:

This article proposes a theoretical model for adapting, for families of children with disabilities, Brooks and Pearce's Self-Sufficiency Standard (2000). With regard to such families, three additional components are considered: increased out-of-pocket expenditures, lost wages for caregiving, and cost of advocacy. Like the Self-Sufficiency Standard itself, this adaptation does not propose an extravagant or even comfortable lifestyle. Instead, this model extends Brooks and Pearce's advocacy agenda by estimating the relative costs of obtaining basic necessities and supports for families raising children with disabilities and by providing clear direction for community engagement in family economic policy.

Keywords: disability, poverty, federal poverty measure, living wage, self-sufficiency, mothering.

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The Cost of Disability Advocacy: Adjusting the Self-Sufficiency Standard for Children with Disabilities

Crafted in the 1960s, the federal poverty measure is the means by which federal programs determine eligibility for financial, medical, and housing supports. It is also the standard against which state, local, and charitable organizations often determine distribution of need-based aid. It is a primary gateway to accessing services and supports for some of the most vulnerable citizens. Yet, methodological gaps in the federal poverty measure seriously undervalue contemporary demands on family income, excluding many from the nation's poverty statistics (Wilson 1991; Slesnick 1993; Betson and Warlick 1998; Jorgenson 1998; Brady 2003; Emerson 2004). Families with complex needs, such as those with children who have disabilities, are particularly vulnerable to the flaws in federal poverty calculations.

Governmental attempts to amend outdated poverty formulae have had limited success (Brady 2003) or have only advisory power, as is the case with the U.S. Census Bureau's Supplemental Poverty Measure (U.S. Census Bureau 2014). Therefore, alternative, privately developed measures of economic necessity are gaining favor among advocates and community-based programs, such as Brooks and Pearce's Self-Sufficiency Standard (2000). Whereas the federal poverty measure is based on an absolute standard of material deprivation, the Self-Sufficiency Standard calculates the costs of financial autonomy that does not sacrifice one basic necessity for another. Taking into account family size, life cycle, and location, it is a method for determining an hourly living wage that is intended to respond to "real-world assumptions" and to allow families to maintain a minimum level of "economic independence" rather than estimating a maximum level of government dependence (Center for Women's Welfare 2015).

Yet, even this progressive measure of cost accounting seriously underestimates contemporary demands on family income in the case of families raising children with disabilities. The Self-Sufficiency Standard does not cite the weight of health care, education,

and child care costs associated with the presence of childhood disability. Moreover, the Standard does not calculate lost wages of working-age adults who meet the increased caregiving needs of children with disabilities (Shearn and Todd 2000; Powers 2001; Porterfield 2002; Corman et al. 2003; Sacco et al. 2013).

Economists and policy advocates recently have argued for the need to analyze the contributions of nonmarket labor to the development of human capital, specifically via parenting (Folbre 1994; Corman et al. 2003; Sacco et al. 2013). The amount of this nonmarket labor grows exponentially with children's disabilities and concomitant social norms pressuring mothers to put energy toward therapeutic resources on behalf of their children (Blum 2007; Landsman 2009; Sousa 2011, 2015). The intensive parenting standard (Hays 1996), placed primarily on mothers of children with disabilities, requires a greater expenditure of family time and resources. The complexity of the disability bureaucracy further demands thoughtful and time-consuming parental advocacy within governmental, educational, and medical institutions that often impose contradictory standards for access to services.

Despite the cultural directive to engage in intensive, advocacy-focused parenting, this nonmarket labor is omitted from both poverty and self-sufficiency calculations, impacting access to resources for both low-income and affluent families who struggle with disability. This article makes the case for expanding the Self-Sufficiency Wage calculations to reflect the real economic burdens faced by families raising children with disabilities, emphasizing the financial burden of parental advocacy within disability bureaucracies.

Literature Review

Jennifer Brooks and Diana Pearce (2000) first published the Self-Sufficiency Standard in *The Clearinghouse Review* as an alternative to the unsalvageable federal poverty measure. The Standard is an attempt to measure "the real cost of living," emphasizing the income needed for families of various compositions to make ends meet in their geographic locations (Pearce 2011). The measure is relative, modified to reflect economic variations in dozens of states using federally available data with location-specific fluctuations in price and availability of goods and services (Wider Opportunities for Women 2011). More than an arcane scholarly work, the Standard offers baselines for household budgeting, provides guidance to policymakers on how to target resources, and gives insight to antipoverty advocates to propel policy agendas that benefit struggling families (Wider Opportunities for Women 2011; Center for Women's Welfare 2015). Similar to David Brady's 2003 critique of the poverty measure, the Self-Sufficiency Standard reflects an understanding of poverty as a condition that excludes families from participation in common and necessary activities of daily living. The specificity of the Standard aims to underscore the relative nature of this exclusion from economic stability, grounding it in families' community environments. Yet if Brady's recommendations are to be realized, then the level of social exclusion associated with poverty should be sensitive to disability.

Pearce recognizes the intersectionality of oppressions that result in social exclusion and reduced economic sufficiency, including disability. In the Self-Sufficiency report for New Jersey, Diana Pearce (2008:27) applies two models for estimating the increased costs associated with adult disability. First, Pearce applies Burchardt and Zaidi's (2003) approach, which calculates a differential cost of disability using a three-tiered scale: low, medium, and high severity. Pearce also applies the techniques used by Noel Smith et al. (2004) to calculate the cost of disability for a single adult with low-medium, medium-high, and intermittent needs as well as

for a single adult with a hearing impairment or vision impairment. Unfortunately, Pearce (2008:28) does not similarly estimate the added costs for children with disabilities; instead, she laments that comparable economic models do not exist to examine childhood disability.

Pearce's complaint is legitimate; there are no comprehensive models for estimating the full impact childhood disability has on family economic security. However, there are numerous studies that gauge aspects of that impact, which are relevant to the Self-Sufficiency Standard. For example, Newacheck et al. (2004) estimate the annual health care expenditure for typically developing children at approximately \$676; but for children with disabilities, the expense is \$2,669. Likewise, Shattuck and Parish (2008) approximate that out-of-pocket health care expenses are 91.2 percent greater for children with disabilities than for their typical peers, excluding lost wage estimates for caretaking, transportation costs, and supplemental educational programs.

Since the passage of the Patient Protection and Affordable Care Act (ACA), numerous efforts have been made to estimate the cost of particular illnesses, including mental illness (Bloom et al. 2011) and Fragile X Syndrome (Sacco et al. 2013). These estimates have limited utility, as they measure specific expenses associated with health care rather than the overall financial burden of disability. Instead of this piecemeal approach, Pearce (2008) suggests that researchers consider the following to construct a comprehensive assessment of the financial burden placed on parents of children with disabilities: (1) increased out-of-pocket expenses such as food, health care, transportation, and housing costs; (2) how means-tested public benefits, such as food stamps, impact family finances, and (3) opportunity costs, such as "parent care," that can prevent at least one adult in the family from full workforce participation. This article

draws on cross-disciplinary literature throughout the analysis to discern an approach to fulfilling Pearce's call for a comprehensive assessment of financial burdens.

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The term "disability" is amorphous; its definition is subject to some level of change, depending on cultural norms, practical demands, and eligibility criteria for programs and benefits, e.g., the nature and severity of impairment or the duration of the condition. According to the U.S. Census Bureau, more than 5 percent of school-aged children are reported to have a disability (Breault 2011). The U.S. Census Bureau defines childhood disability in relation to a child's need for special approaches to vision, hearing, cognition, mobility, or independent living. Other government programs offer differing definitions that range from broad to specific. For example, a child with mild dyslexia may be considered educationally disabled while a non-ambulatory child on a ventilator and feeding tube also would be considered disabled in a number of contexts. Each child has functional limitations; yet, the costs associated with raising these two children are considerably different. As a result, there are numerous methods of categorizing the impact of such costs, many of which estimate the severity of disability and associate greater severity with greater cost.

This study relies on Elise Gould's (2004) framework, in which three categories of costs are considered. Gould suggests that some children have illnesses that require expensive treatment but demand limited parental time. Other children require high levels of parental involvement in day-to-day care but less costly treatment. Finally, some children have unpredictable, episodic illnesses, such as epilepsy or mental health problems, that require parent time and/or high expenditures with irregular frequency. Of course, children's needs commonly cross these lines. The child needing a ventilator and feeding tube would require intensive

caregiving as well as expensive medicine and equipment. The probability of pneumonia and other illnesses adds a level of unpredictability to this child's care as well. Using Gould's (2004) research as a theoretical basis, this study itemizes high out-of-pocket and opportunity costs, in order to allow parents, advocates, and policymakers to ascertain which costs are most likely to impact a particular family at any given time. This approach offers greater flexibility and utility than a simple three-pronged approach, allowing for financial calculations based on a broad range of disabling conditions. Therefore, the parents of the child needing a ventilator and feeding tube may use elevated estimates in each category to determine budgetary needs, while the parents of the child with mild dyslexia may use only elevated educational costs to inform their estimate.

Out-of-pocket expenditures

Using the Self-Sufficiency Standard methodology as a baseline, the following data reflect estimates of out-of-pocket expenditures related to disability using existing scholarly or credible sources and are calculated to target a minimally adequate level for family economic survival (Brooks and Pearce 2000). These estimates are imperfect as they rely on developing research; however, they offer a foundation for estimating the financial impact of childhood disability on family economic security.

(1) Transportation: The Self-Sufficiency Standard calculates the costs of transportation using two different formulae. First, public transportation costs are calculated, where available, using the cost of a two-zone pass. If public transit is not available, the costs of owning and operating a car are calculated based on the American Automobile Association, the National Household Travel Survey, the National Association of Insurance Commissioners, and the Consumer Expenditure Survey. Geographic variation in insurance costs is calculated using the median rate from the top five carriers in the state (Pearce 2008).

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The national inadequacy of public transit options is of immense concern to people with disabilities, as they are more than twice as likely to consider inadequate transportation as a problem as their non-disabled peers (National Organization on Disability 2004). However, some areas of the nation have public transit systems that meet the needs of a wide range of passengers. In these cases, the Self-Sufficiency Standard's calculation of public transit costs may be an accurate portrayal for some families raising children with disabilities, but the assessment should emphasize accessible transportation. In the event that transportation is not accessible for people with disabilities, the calculation should include the costs of operating and maintaining a personal vehicle with a wheelchair lift/ramp or one that has options to add other custom features. This inclusion of private transportation costs may also be necessary when transportation is mobility accessible but is not a viable choice for some due to disabilities such as sensory processing disorders.

The data sources currently employed by the Self-Sufficiency Standard may be utilized to incorporate the costs of owning and operating larger, more easily modified vehicles for people with disabilities. The additional equipment costs for vehicle modification may be calculated by utilizing state level market data. While the costs associated with modifying a vehicle vary greatly, such fluctuations are limited when the costs are calculated within this context. It is less likely that a minor child with a disability would need adaptive vehicle control products; instead, vehicle modification costs are more likely associated with wheelchair access and passenger lifts. This reduces the complexity of collecting geographically specific market data. In addition, state vehicle registration costs as well as sales and excise taxes are publicly available information easily accessed in a cursory state level data search.

Beyond the manifest expenses of transportation for children with disabilities, several added costs of transportation may be hidden in other line items. For example, a family may need to endure the expense of moving to a location with more accessible public transit (i.e., to a location in the immediate vicinity of public transit with level terrain and mobility accessible sidewalks). These property features come at a premium and, thus, reflect higher housing costs as a direct result of transportation needs. Furthermore, transportation costs may be disguised as opportunity costs for parents transporting disabled children to field trips, extracurricular activities, therapy appointments, or even school. Those latent expenses are outlined in subsequent sections.

(2) Housing: The Self-Sufficiency Standard estimates the cost of rent and utilities based on the Fair Market Rents calculated by the U.S. Department of Housing and Urban Development (HUD). Estimates for locales are adjusted for specific geographic areas, using ratios based on median gross rents from U.S. Census data, calculated by the National Low Income Housing Coalition (Pearce 2008, 2011). Rental price calculation is challenging in a fluctuating market, particularly when more than 66 percent of U.S. housing stock is owned, with the majority being single family housing (Cooper et al. 2009) not subject to the Fair Housing Amendments Act of 1988 (Achtenberg 2004). There are no federal building accessibility requirements for single family residential settings, and building codes vary from state to state.

The challenge of finding affordable rental property is elevated for families raising children with disabilities, as most of this housing stock has features that limit basic access, such as raised porches, threshold steps, and narrow bathroom doors (Cooper et al. 2009). Retrofitting these features in a home is costly (Cooper et al. 2009). Some common alterations to make a home suitable for someone with a disability include widening doorways and corridors; adjusting

the height of electrical switches, phones, and door handles; adding grab rails and railings; and constructing special bathroom facilities with higher toilets, ground floor access, level deck showers, and/or bathtubs with hoists.

The American Association on Mental Retardation (AAMR) reports that the average out-of-pocket expenses to modify physical surroundings totaled about \$100 for children with autism and about \$250 for children with severe mental retardation (Birenbaum and Cohen 2002:353). These expenses do not include extreme and specific instances of modifications such as the redesign of a home's interior, structural modifications for wheelchair access, or the placement of alarmed windows and bolted doors to prevent a child from running away (Birenbaum and Cohen 2002:353). The AAMR further reports that about 10 percent of families studied had home and car modifications whose costs exceeded \$2,000 per year (Birenbaum and Cohen 2002:353). Additionally, the AAMR reports that about 10 percent of families interviewed spent \$350 per year to replace damaged furnishings (Birenbaum and Cohen 2002:354).

While moving to a more accessible property may be a more economical alternative, universally designed homes are in limited supply. Additionally, moving may be required to gain stronger community supports and social networks for children with disabilities. As previously indicated, lack of transportation may force an individual with a disability to relocate to an area with more accessible public transportation services (Enders and Seeker 2009). The last consideration favors urban areas with public transit and concomitantly higher housing prices. A recent study in Indiana suggests that higher "urban costs of living are offset by higher incomes" and that the "cost of living in rural areas is generally in proportion to...lower incomes" (Center for Regional Development et al. 2007:Appendix IV). However, families moving to urban areas in search of accessibility for children with disabilities may not engage in an employment change

yielding higher wages. Under these circumstances, families may accrue more costs for housing and added commuting time while maintaining a stagnant wage.

Most national moving van companies, including Uhaul and Budget Truck Rental, offer online estimates for moving vans and boxes in local areas based upon the number of bedrooms in a home. State public utility commissions offer data on connection fees and deposits for utilities. Finally, the Self-Sufficiency Standard itself offers analysis of rental markets that can be used to calculate the costs of first and last month rental deposits.

(3) Child care: The Self-Sufficiency Standard calculates the cost of child care based on the 75th percentile of state market rate surveys by age, setting, and place (Pearce 2008). Federal law attempts to make these same child care providers accessible to children with disabilities. The Americans with Disabilities Act (ADA) prohibits child care providers from discrimination on the basis of disability, unless a child's presence would pose a direct threat to the health or safety of others or requires fundamental alteration of the program. Child care centers are also required to make "reasonable modifications" to their policies and practices to integrate children and family members with disabilities into their programs unless doing so would constitute a "fundamental alteration" of the program (U.S. Internal Revenue Service 2011).

While individual families may not be charged for program modifications required by the ADA, many children's needs go beyond the ADA protections offered and, therefore, require specialized care for which families may be assessed additional charges (U.S. Internal Revenue Service 2011). For example, if a child requires complicated medical procedures performed only by licensed medical personnel, the child care program would not be required to provide the medical services under the ADA. Likewise, a child with behavioral or emotional challenges who hits, screams excessively, bites, or thrashes may not be welcomed in a child care facility. For

children with limited communication skills, these behaviors may be a means of communication, but, at the same time, may present significant burdens to traditional day care programs. In these events, specialized child care may be necessary in the form of a registered nurse or a behavioral specialist. Information about the mean and median hourly pay rates for these professions, as well as for nurse's aides and home health care providers, is available through the U.S. Bureau of Labor Statistics. In addition, the Bureau calculates the 10th, 25th, 75th, and 90th percentile wages. For consistency with the Standard's current methodology, it is reasonable to estimate this labor at the 75th percentile for 45 hours per week, which covers five eight-hour work days as well as one hour of commuting time per day.

Additionally, the cost of day care may not be reduced with age as suggested by the Self-Sufficiency Standard; instead, there may be a continuous need for heightened levels of adult oversight. Thus, these families may not experience the same reduction in day care costs as families with typically developing school-aged children.

(4) **Food:** The Self-Sufficiency Standard estimates the cost of food using the U.S. Department of Agriculture's Low-Cost Food Plan. The Standard accounts for geographic differences in costs using The Council for Community and Economic Research's Cost of Living Index (Pearce 2008). This approach to food costs is modest at best and assumes that all family members are capable of consuming most commercially produced food products. However, a variety of chronic illnesses and disabilities necessitate that nutritional requirements be met under specific circumstances that are not outlined in the Low-Cost Food Plan. For that reason, food costs for children with disabilities can be broken down into three categories of nutritional consumption: liquid, restricted solid, and fortified solid diets.

Liquid Diet: Some children with disabilities are not able to chew, swallow, and/or digest solid foods; so nutrition is delivered through a liquid diet or “formula” specifically designed to meet the needs of children beyond infancy. This form of consumption is often associated with percutaneous endoscopic gastrostomy (PEG). Callahan and colleagues (2001) estimate that costs of commercial formulas range from \$1.00 to \$2.00 per can with approximately six to eight cans consumed per day, while costs of homemade formulas average between \$5.00 and \$8.00 per day. Additionally, the average daily cost of PEG-tube feeding and labor to provide feeding was approximately \$90 in 2000 with spotty insurance reimbursement (Callahan et al. 2001). Overall, Callahan et al. (2001) estimate that the cost of providing feeding via PEG for one year was \$31,832 in 2000. The primary components of this cost include the initial PEG procedure, formula, and hospital charges for major complications (Callahan et al. 2001). These price estimates provide a solid baseline for supplementing the Self-Sufficiency Standard’s price index; however, the estimates should be adjusted for over a decade of cost inflation.

Restricted Solid Diet: Some children with disabilities are able to chew and swallow solid foods; however, allergies and/or difficulty digesting some standard products require specialized diets. A common diagnosis requiring a limited diet is celiac disease. While not exclusive to children with autism spectrum disorders, the dietary treatment for celiac disease is increasingly used with children on the spectrum (Genuis and Bouchard 2009). The primary treatment for celiac disease is an avoidance of products containing gluten. Gluten-free versions of standards like bread, pancakes, and crackers are approximately twice as expensive as widely consumed commercial products (Lee et al. 2007).

While some of these foodstuffs may be cooked from scratch using gluten substitutes, the time needed to prepare these products results in increased opportunity costs. For example, the

U.S. Bureau of Labor Statistics estimates the cost of a generic loaf of white bread in Boston, Massachusetts, at \$1.49 per pound, while the average cost of a gluten-free loaf of bread in the same area is \$4.94 per pound (June 2011). Producing gluten-free bread at home is even more costly. The expense of raw materials is added to one hour of labor to bake a loaf of gluten-free bread times the hourly self-sufficiency wage of Boston. Assuming that the average household oven has the capacity to bake four loaves of bread at one time, the cost of one loaf of homemade, gluten-free bread is \$9.40, with higher upfront costs of buying excess raw materials such as xanthan gum (a thickening agent often used as a gluten substitute) and gluten-free flour.ⁱ Thus, it is both reasonable and economical to use commercial estimates of costs of gluten-free groceries at three times the general rate for supplementing the Self-Sufficiency Standard's food expenditure.

Fortified Solid Diet: Some children with disabilities are able to eat solid foods without allergic or digestive reactions; however, they may not receive proper nutrition through eating alone. Oral-motor weakness and sensory sensitivity are examples of challenges that may limit the variety of foods a child will consume, resulting in nutritional deficits. Similarly, children with albinism may not get enough Vitamin D due to reduced exposure to sunlight. Several commercial products exist to mitigate these difficulties, including chewable vitamins and fortified nutritional drinks. The National Institutes of Health Office on Dietary Supplements (2005) indicates that more than 30 percent of American children take some kind of dietary supplement. Regional market data may be used to calculate the daily cost of one multivitamin and one nutritional drink per day to add to the estimate of the total cost of food.

Many children who fall into these three categories may benefit from feeding programs structured by licensed occupational therapists. This kind of therapeutic expenditure is

considered under health care rather than food expenditures; however, a geographically specific estimate of this cost may be obtained by multiplying the average hourly rate for a qualified, licensed occupational therapist by the time needed to develop, execute, evaluate, and report on the efficacy of the feeding program.

(5) Health care: The Self-Sufficiency Standard employs data calculated by the U.S. Medical Expenditure Panel Survey to assess health care premiums and out-of-pocket costs. Additional data are used to document geographical differences in health care costs when available. Health care is particularly important for families raising children with disabilities and/or special health care needs, as more than 33 percent of these families report their current health coverage is inadequate in covering their costs (Farrell et al. 2011). This proportion is higher still among those whose children have specific diagnoses such as epilepsy (Farrell et al. 2011).

Ideally, data subsequent to the passage of the Patient Protection and Affordable Care Act will demonstrate an increase in the adequacy and affordability of health insurance coverage for children with disabilities. Under the ACA, insurance companies are prohibited from denying coverage to people with preexisting conditions, like many children with disabilities. In addition, under the ACA, health insurance plans must cover several preventative services without charging consumers. The Association of Maternal and Child Health Programs (AMCHP) highlights the importance to children with disabilities “because it removes cost as a potential barrier to early diagnosis, which is critical to effective treatment” (AMCHP 2012:4). However, even with the passage of ACA, there is reason to believe that affordability of coverage will continue to be an economic barrier to caretakers of children with disabilities. Out-of-pocket costs for care and high cost sharing can mean that some children may “have limited or no access to needed health

care services and supports” (AMCHP 2012:3). Thus, as data continue to emerge post ACA, it will remain important for families to assess the economic impact of illness and disability on their health care budgets.

One such method of assessment is the cost-of-illness (COI) approach, adding both direct and indirect costs of medical care, which includes the following: personal medical care costs for diagnosis, procedures, drugs, and inpatient/outpatient care; non-medical costs, such as transportation for treatment and care; non-personal costs associated with information, education, communication and research; and income losses (Bloom et al. 2011).

Sacco et al. (2013) use a COI analysis to determine the annual out-of-pocket costs for patients with Fragile X Syndrome, which ranged between \$2,222 and \$9,702, depending on the health insurance carrier and the number of procedures and/or hospitalizations in a given year.

The COI approach is specific to a particular diagnosis or class of diagnoses, which lends itself to high validity, but is subject to real-time cost analysis of particular illnesses. This makes it difficult to use universally due to the burden of calculating and recalculating costs across a large population. For example, Bloom et al. (2011) conducted global COI estimates for non-communicable diseases, but failed to create a solid COI analysis for mental illness due to a dearth of reliable support data. Given that mental illness constitutes “the greatest global burden in terms of disability,” the specificity of this measure is outweighed, in some cases, by the lack of accessible data (Bloom et al. 2011:26).

Alternatively, several studies attempt to estimate added costs of health care for children with special needs using a “flat rate” approach. Shattuck and Parish (2008) estimate these supplemental out-of-pocket healthcare costs for children with chronic illnesses and/or disabilities at a state level. Adjusted state-level means range from \$562 to \$972 of additional out-of-pocket

health care expense per child annually (Shattuck and Parish 2008); however, these estimates do not include the costs of fronting the money for services while insurance eligibility or appeals are processed or while families are on waiting lists for services such as home based care, nursing care, specialized therapeutic care, and feeding programs. In other words, this adaptation to the Self-Sufficiency Standard provides a basic starting point for estimating added costs of health care, but does not provide a financial cushion to mitigate bureaucratic challenges of accessing that care.

(6) Miscellaneous Expenses: The Self-Sufficiency Standard reserves 10 percent of funds for miscellaneous expenses, including all other essentials, such as clothing, shoes, diapers, nonprescription medicines, household items, and telephone (Pearce 2008). This catch-all category is challenging to modify without specific methodology for replication and without clear cost data on daily needs of individual children. However, families and advocates should be wary of potential expenditures, including the following: prolonged use of diapers; extended use of over-the-counter medications such as laxatives, stool softeners, gas relief, cold/congestion medications to prevent aspiration, and allergy medications; frequent clothing purchases for items soiled through falls, spills, and/or bathroom accidents; sensory-specific clothing and personal items such as body socks, weighted blankets, and compression clothing; modified tools for individual rather than family use, such as triangular pencils and thicker utensils; adaptive seating, such as yoga balls, rubber wedges, and adaptive chairs; non-insurance-covered medical devices, such as hearing aids or implants; and, perhaps, additional expenses for toiletries and bedding as well.

(7) Taxes and Tax Credits: The Self-Sufficiency Standard calculates the federal and state tax burden on families as well as tax credits, including state sales and income taxes as well as the

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federal Earned Income Tax Credit, the Child Care Tax Credit, and the Child Tax Credit (Pearce 2008). These taxes and tax credits may also apply to families raising children with disabilities. In addition, these families may be able to deduct some disability-related medical expenses from federal tax returns. If a family itemizes its federal tax return and its yearly medical expenses exceed 7.5 percent of the adjusted gross income, certain qualified expenses may be deducted from the federal tax rate. For example, diapers may be a deductible expense if needed to relieve the effects of a particular illness. Costs associated with transportation to medical facilities may be deducted. Even some home improvements may be deducted given demonstrable medical need, provided they are specialty equipment installed in a home, such as entrance ramps, wider doorways, additional railings, and accessible electrical outlets and lighting. The cost of permanent improvements, once reduced by the increase in value of the property, may be included as a medical expense. (Internal Revenue Service 2011).

These tax benefits must be weighed against the complexity of the tax code for deducting disability related expenses. In order to accrue these deductions, it is reasonable to assume that families will incur professional tax preparation expenses as most low-cost, tax preparation software packages are unfit to handle this level of complexity. The U.S. Bureau of Labor Statistics offers hourly rates for tax preparation. Unfortunately, this investment has no clear calculation for return: tax preparation expenditures do not guarantee tax refunds. Even if tax refunds are possible they are paid annually, forcing families to prepay disability-related medical expenses.

Means-tested Disability Benefits

Several public benefits programs for people with disabilities target resources using an income threshold. Medicaid and SSI are examples of means-tested benefits; however, assessing

the point at which such benefits disappear is not as simple as adding costs once family income reaches a particular maximum. States have flexibility in administering these federal benefits and, thus, have a variety of practices for assessing income. New Hampshire, for example, assesses only the income of the person or, in this case, the child with a disability to determine eligibility for Medicaid; family income is not considered. As a result, poor and wealthy families alike may obtain Medicaid health benefits for children with severe disabilities in New Hampshire (New Hampshire Department of Health and Human Services 2011). Alternatively, Virginia uses family income to determine sliding-scale fees for some early-intervention services (Fairfax County 2011). Moreover, because these programs serve so many constituencies, they are constantly being augmented or cut to accommodate state and federal budgets under political and economic pressures (Aron and Loprest 2007). Thus, any discussion of means-tested benefits must be related to a state-by-state assessment of programmatic resources, including federal, state, municipal, and charitable programming, and must be updated frequently to capture the true impact of programming on family finances.

Such an assessment would be a useful resource for families raising children with disabilities; however, the utility of this information is ambiguous in establishing a Self-Sufficiency Standard. The Self-Sufficiency Standard was initially designed to determine family economic viability without public or private assistance (Pearce 2011). Yet, the author calls for an assessment of means-tested benefits when calculating the Standard for children with disabilities (Pearce 2008). It seems as though Pearce is proposing a double-Standard that assumes people with disabilities should have a greater reliance on public benefits than people without disabilities. While this may often be the case, the Standard, as an advocacy tool, was designed to ascertain the point at which families may achieve economic independence from

governmental sources. For that reason, this study does not calculate differential costs based upon means-tested benefits, thus adhering to the intent of the Self-Sufficiency Standard. As a matter of equity, this goal should not function differently for families raising children with disabilities.

Opportunity Costs

Numerous studies have considered how parents' market-labor participation is impacted by caring for children with disabilities (e.g., Salkever 1985; Cuskelly et al. 1998; Kimmel 1998; Lewis et al. 2000; Shearn and Todd 2000; Powers 2001; Porterfield 2002; Corman et al. 2003; Bednarket and Hudson 2003; Gould 2004; Sacco et al. 2013). Parents must devote increased time to oversight of activities of daily living, functional tasks, education, medical evaluation, and therapeutic care. This time extends to transportation to appointments as well as prolonged child care and potential adult care responsibilities. While not all parents perform all of this care themselves, they must continue to expend time and energy coordinating family members, friends, or professionals to undertake the added care-work. The findings of these studies are fairly consistent in indicating reduced probabilities of paid work participation by married mothers of children with disabilities as well as fewer paid-work hours.

Some studies indicate that the strength of the estimated association between the child's disability and the mother's paid work varies according to diagnosis and severity of the child's disability. For example, a Canadian study indicates that the probability of a parent's not taking a job is 36.1 percent higher when the parent's child has a very severe, compared with a mild, condition (Burton and Phipps 2009). In the United States, Meyers et al. (2000) found that mothers with more than one moderately disabled child or with at least one severely disabled child were 20 to 30 percent less likely to have worked in the previous month than mothers with healthier children. Leonard et al. (1992) found that family income did little to influence this

caregiving burden on families. They did not find the expected inverse relationship between income and time spent caregiving. In other words, time could not be substituted for money:

Contrary to assumptions, income was not found to be significant in establishing the burden to families. Income level was not statistically significant in predicting time and out-of-pocket expenses (Leonard et al. 1992: 310).

Yet other studies indicate greater negative impacts on workforce participation for lower-income mothers (Salkever 1982) and unmarried mothers (Corman et al 2003).

This variation makes calculating opportunity costs challenging; however, the conflict among studies concerns not *whether* raising a child with a disability increases opportunity costs but, rather, *how much* caregiving work detracts from paid labor. Michael Keane (2010) aptly contends that "all econometric work relies heavily on *a priori* assumptions." The theoretical integrity of the process, he continues, is not in the number of assumptions but in "the extent to which they are made explicit." Following Keane's dictum, estimates of opportunity costs rely on research consensus in three areas: caregivers are equally likely to be in the labor force as other adults prior to introduction of the child in need of special care; caregivers are more likely to work fewer hours in the labor market than peers, particularly if their children's disabilities are severe; and those heavily involved in caregiving are significantly more likely than others to withdraw from the labor market (Lilly et al. 2007).

There is no comprehensive, national caregiving data spanning multiple disability diagnoses; however, recent research on caregivers of children with spina bifida indicates that caregivers work an annual average of 7.5 to 11.3 hours less per week depending on disability severity. Similarly, research by Sacco et al. (2013) estimates that caregivers of children with Fragile X Syndrome needed an average of 19.4 hours away from work monthly to care for their

children's needs. Similar findings by Corman et. al. (2003), indicate that these mothers worked an average of four hours less per week. Thus, the opportunity cost of caring for a child with a disability may be estimated roughly by multiplying four hours per week of foregone labor by the Self-Sufficiency hourly wage and may be modified using a more diagnosis-specific estimate in some cases.

The Case for Advocacy

Over the course of the last half-century, a host of legislative and executive enactments have been developed to provide legal rights and services to people with disabilities and their caregivers with the intent of securing the participation, inclusion, and integration of people with disabilities into all aspects of society. Federal, state, and local government bodies have established elaborate bureaucratic systems to implement these legal protections and oversee myriad supportive, educational, and therapeutic programming. As a result, caregivers are required to develop “specialized knowledge in varied medical and nonmedical fields, including law, education, behavior analysis, pharmacology, sensory integration, motor therapies, and bureaucratic minutia” to assist their children in making desired gains (Sousa 2015). Navigating these professional systems requires considerable time, education, and resources, which are often redirected from income-generating endeavors (Corman et al. 2003; Sacco et al. 2013).

Beyond medical, educational, and therapeutic expertise, children's needs must include the caregiver's ability to navigate the bureaucratic requirements of programs designated to assist people with disabilities (Blum 2007; Landsman 2009; Sousa 2011, 2015). Mastery of the requirements for one program does not necessarily equal knowledge of rules for another. Instead, parents are responsible for crossing the territorial lines of disability bureaucracies, in which

program rules are inconsistent and no single expert exists on the system as a whole (Aron and Loprest 2007).

Even the three largest federal programs that undergird the disability bureaucracy—Medicaid, Supplemental Security Income, and the Individuals with Disabilities Education Improvement Act—employ different terms, definitions, and criteria for defining and classifying disabilities among children, determining eligibility, and designating families' economic needs for publicly funded services (Aron et al. 1996; Aron and Loprest 2007).ⁱⁱ

Program rules do not agree on the definition of a child, never mind the vast intricacies of application and eligibility. These legal complexities are amplified by the poor coordination of systems administered by a patchwork of agencies, each with its own rules. More than 20 agencies oversee nearly 200 programs targeted to people with disabilities (Aron et al. 1996; Aron and Loprest 2007), including the Departments of Justice, Health and Human Services, Treasury, Housing and Urban Development, Agriculture, Education, Labor, and Transportation as well as the Federal Communications Commission and the Social Security Administration, to name only a few. Each of the programs offered is governed by federal laws and regulations as well as procedural requirements for application, complaint, and appeal, which differ in process and intent.

Beyond the federal quagmire, state agencies are authorized to carry out many aspects of federal disability programs. For example, states have the option to automatically provide SSI Related Medicaid to recipients through the SSI program. Ten states use at least one eligibility criterion that is more restrictive than the SSI program for Medicaid eligibility; thus, SSI recipients in those states must make separate applications for Medicaid coverage. Those who live in the other states do not have to file separately. Furthermore, in a survey of seven 209(b)

states, Health and Disability Advocates (HAD) found that Medicaid provider packages are different depending on whether the insured party receives SSI Related Medicaid or ACA Related Medicaid (Entwisle 2015). Discerning the difference is up to the consumer, or, in this case, the parent.

Local agencies, such as schools, welfare offices, and health care providers then interpret the systems' precepts within the contexts of normative structures that vary from community to community. Although this federalist approach distributes administrative power to meet needs in a community-specific manner (Keiser 2006), it also gives power to myriad officials to create divergent tools that are challenging to comprehend. Children with the same needs and circumstances can receive different benefits and services due to geographic variation in program rules (Aron and Loprest 2007). Even municipalities within the same state can have different approaches and staff configurations to execute state mandates. Simply moving to a bordering town can result in significant financial and service adjustments for families with little-to-no guidance in maneuvering these changes.

The result of this complexity is the expenditure of an extraordinary amount of time and resources engaging various aspects of the system; acquiring formal and informal knowledge about the intricacies of these systems; communicating in person, by phone, and by email with bureaucrats from these agencies; and, of course, waiting for responses. While these efforts take time away from income-generating activities, they also deny families opportunities for leisure and rest, exacerbating child, family, and parental stress. Viewed broadly, these efforts can be seen as opportunity costs; however, they are not costs directly associated with disability or therapeutic intervention. Instead, advocacy costs are a result of bureaucratic inefficiency and could be alleviated, not by mitigating disability, but through streamlining a complex system of

program administration “in need of urgent attention and organizational transformation to ensure that programs function in the most economical, efficient, and effective manner possible” (U.S. Government Accountability Office 2005).

In the absence of government overhaul—a prospect that appears unlikely in the near future—it is reasonable to incorporate the costs of advocacy into the daily expenditures of families raising children with disabilities. Certainly some families exercise greater capacity and effort than others on this endeavor; however, the absence of early parental advocacy is unlikely to reduce the overall cost impact of disability to society generally. It is more likely that, in the absence of parental advocacy, costs simply shift to the individual with disability in the form of reduced wages in the labor market, and to the public in the form of extended adult service programs for people with disabilities. It makes fiscal sense to invest advocacy and funding early in a child’s development, which can ultimately “generate significant savings for society at large” (Aron and Loprest 2007:5).

The inclusion of advocacy costs in the Self-Sufficiency Standard would produce a resource for developing prudent fiscal and governmental policies for families raising children with disabilities. Unfortunately, there is not a study that differentiates the opportunity costs of disability, such as transportation, parent care, and acquiring medical treatments, from the advocacy costs of convoluted bureaucracies, such as fighting insurance claim denials, learning arbitrary eligibility rules for multiple programs, and researching various programs housed and referred to in multiple agencies. A large-scale time study of parents of children with disabilities, with careful attention to the methodological challenges, would be the most direct means of attaining this information (Silberstein and Scott 1991). This calculation could then be multiplied by the Self-Sufficiency Wage to estimate the cost of advocacy. In the absence of such a study,

the opportunity costs must suffice for estimating the expenses of parental advocacy, yielding a continued underestimation of the cost of childhood disability for families.

Conclusion

The Self-Sufficiency Standard highlights the exorbitant costs of raising children with disabilities as compared with the meager wages proposed by the federal poverty measure. The income gap between federal programming and the more realistic Self-Sufficiency Wage exerts tremendous economic pressure on individuals and families who occupy the space between the Standard and the poverty line and who do not qualify for government assistance. Yet, even the Self-Sufficiency Standard vastly underestimates the impact of childhood disability on families' economic well-being—the increased financial and emotional stress for families unable to make ends meet.

In spite of these pressures, parents, and mothers in particular, are urged to take on increased unpaid labor through family caregiving regardless of the cost or the availability of a sustainable wage. American mothers are expected to parent with “intensity,” devoting limitless time, energy, and resources to their children’s development while disregarding any self-interest that may conflict with their children’s needs and desires (Hays 1996). Mothers of children with disabilities are often persuaded to take on even more non-market responsibility by incurring the roles of vigilante (Blum 2007) and warrior-hero (Sousa 2011, 2015) to garner resources and wage war against frugal bureaucracies holding the keys to childhood development.

Even without a cultural predisposition toward intense maternal obligation, advocacy is a necessary, non-market resource for parents of children with disabilities navigating a muddled, legalistic system of public and private bureaucracies. In concept, the legalization of these bureaucratic systems offers people of varied socio-economic strata the opportunity to advocate

for the programs and services they desire through public systems rather than private resources (Goldberg 1989). In practice, however, considerable evidence indicates that access to legal remedies comes at a premium (Garth 1994; Silver 2002). This suggests that the quality of parents' experiences with bureaucracies may have much to do with their material resources and preparedness to advocate within impersonal, hierarchical institutions, thereby limiting access to those with the material and emotional resources to withstand such complexities. In other words, less experience with these systems likely yields more hours of work to generate outcomes.

As a result, managing a child's disability in a bureaucratic system takes time away from both childrearing and earning a living wage or even a minimum wage; yet, this additional labor is not rewarded. Instead, care work for children with disabilities is an unfunded mandate for some families that results directly from lack of coordination among governmental systems. Meanwhile, families with disabled children often face increased barriers as they "are more likely to have reduced resources because of their limited availability for paid employment" and need "specialized goods and services related to the child's disability or chronic illness" (Meyers et al. 2000).

In short, the estimation that income that may be "sufficient" for a family of four does not account for the out-of-pocket, opportunity, and advocacy expenses associated with raising children with disabilities. Even when the proposed cost factors associated with raising children with special needs are included, there remains a major deficit in self-sufficiency research and policy development in the estimation of the real costs of advocacy for children with disabilities. While the Self-Sufficiency Standard is responsive to family life cycle needs, the relativity of the measure must be increased to represent the specific needs of families raising children with disabilities.

Notes on contributor

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References

- Achtenberg, Roberta. 1994. "HUD Assistant Secretary for Fair Housing and Equal Opportunity Appendix IV to Ch.I, Subchapter A—Questions and Answers about the Fair Housing Accessibility Guidelines Questions and Answers about the Fair Housing Accessibility Guidelines." Washington, DC: US Department of Housing and Urban Development.
- Anderson, Donna, Serge Dumont, Philip Jacobs, and Leila Azzaria. 2007. "The Personal Costs of Caring for a Child with A Disability: A Review of the Literature." *Public Health Report* 122: 3–16.
- Aron, Laudan Y. and Pamela J. Loprest. 2007. *Meeting the Needs of Children with Disabilities*. Washington, DC: Urban Institute Press.
- Aron, Laudan Y., Pamela J. Loprest, and C. Eugene Steurele. 1996. "Serving Children with Disabilities: A Systematic Look at the Programs." Report. Washington, DC: Urban Institute.
- Association of Maternal and Child Health Programs (AMCHP). 2012. "AMCHP Issue Brief: Affordable Care Act and Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities." Washington, DC: Maternal and Child Health Bureau, 1–12. http://www.amchp.org/programsandtopics/CYSHCN/resources/Documents/ACA_AutismFactSheet_5-3-12.pdf#search=Affordable%20Care%20Act%20and%20Children%20and%20Youth
- Birenbaum, Arnold and Herbert J. Cohen. 2002. "On the Importance of Helping Families" in Jan Blacher and Bruce L. Baker's *Families and Mental Retardation: a Selection of Notable AAMR Journal Articles Across the 20th Century*. David Braddock (series editor). Washington, DC: American Association on Mental Retardation. Pp. 351–358.
- Bloom, D. E., E. T. Cafiero, E. Jané-Llopis, S. Abrahams-Gessel, L. R. Bloom, S. Fathima, A. B. Feigl, T. Gaziano, M. Mowafi, A. Pandya, K. Prettnner, L. Rosenberg, B. Seligman, A. Z. Stein, and C. Weinstein. 2011. "The Global Economic Burden of Non-communicable Diseases." Geneva: World Economic Forum. 1–46.
- Blum, Linda. 2007. "Mother Blame in the Prozac Nation: Raising Kids with Invisible Disabilities." *Gender and Society* 21 (2): 202–26.
- Brady, David. 2003. "Rethinking the Sociological Measurement of Poverty." *Social Forces*, 81 (3): 715–752.

- Breault, Matthew W. 2011. "School-Aged Children with Disabilities in U.S. Metropolitan Statistical Area." Report. Washington, DC: U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau, November.
- Brooks, Jennifer, and Diana Pearce. 2000. "Meeting Needs, Measuring Outcomes: The Self-Sufficiency Standard as a Tool for Policy-Making, Evaluation, and Client Counseling." *The Clearinghouse Review* 34 (2000–2001): 34.
- Burchardt, Asghar and Tania Zaidi. 2003. "Comparing Incomes When Needs Differ: Equivalisation for the Extra Costs of Disability in the UK." Report. London, UK: Centre for Analysis of Social Exclusion, London School of Economics, February.
- Burton, Peter and Shelley Phipps. 2009. "Economic Costs of Caring for Children with Disabilities in Canada." *Canadian Public Policy* 35 (3): 269–90.
- Callahan Christopher M., Nancy N. Buchanan, and Timothy E. Stump. 2001. "Healthcare Costs Associated with Percutaneous Endoscopic Gastrostomy Among Older Adults in a Defined Community." *Journal of American Geriatric Society* 49: 1525–1529.
- Center for Regional Development, Purdue University; Indiana Business Research Center, Kelley School of Business, Indiana University; and Strategic Development Group, Inc. 2007. *Unlocking Rural Competitiveness: The Role of Regional Clusters*. Report. U.S. Economic Development Administration and the State of Indiana.
- Center for Women's Welfare. 2015. "The Self-Sufficiency Standard: What a Difference a Measure Makes." University of Washington School of Social Work. Retrieved June 1, 2015 (http://selfsufficiencystandard.org/docs/SSS%20General%20Handout_061909.pdf).
- Cooper, Emily, Henry Korman, Ann O'Hara, and Andrew Zovistoski. 2009. "Priced Out in 2008: The Housing Crisis for People with Disabilities." Report. Washington, DC: Technical Assistance Collaborative, Inc. Consortium for Citizens with Disabilities, Housing Task Force, and *Funded by the Melville Charitable Trust*.
- Corman, Hope, Nancy E. Reichman, and Kelly Noonan. 2003. "Mothers' and Fathers' Labor Supply in Fragile Families: The Role of Child Health." Working Paper 9918. Cambridge, MA: National Bureau of Economic Research.
- Cuskelly, M., L. Pulman, and A. Hayes. 1998. "Parenting and Employment Decisions of Parents with a Preschool Child with a Disability." *Journal of Intellectual and Developmental Disability* 23: 319–333.
- DeNavas-Walt, Carmen; Berandette D. Protctor, and Jessica C. Smith. 2011. "Income, Poverty, and Health Insurance Coverage in the United States: 2010." *U.S. Census Bureau, Current Population Reports, 2010*. Washington, DC: U.S. Government Printing Office, 60–239.
- Enders, Alexandra, and Tom Seekins. 2009. "A Review of FTA Section 5310 Program's State Management plans: A Legacy Program in Transition." Report. Missoula: The University of Montana Rural Institute.
- Entwisle, Joe. 2015. "ACA, Medicaid and Unintended Consequences for People with Disabilities." *Illinois Health Matters*. Tuesday, April 28, 2015. <http://illinoishealthmatters.blogspot.com/2015/04/aca-medicaid-and-unintended.html>
- Fairfax County. 2011. "Service Profile." www.fairfaxcounty.gov. Retrieved May 17, 2011. (<http://www.fairfaxcounty.gov/rim/servicedetail.asp?orgsrn=1547&svcrsn=7568&locrsn=3742&svcname=EARLY+INTERVENTION++CHILDREN&orgname=INFANT+%26+TODDLER+CONNECTION+OF+FAIRFAX-FALLS+CHURCH>).

- Farrell, Kathleen. 2011. "The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers." Webinar presented by the National Academy for State Health Policy with the support of the Catalyst Center at Boston University. Jan. 27.
- Folbre, Nancy. 1994. "Children as Public Goods." *The American Economic Review* 84 (2): 86–90.
- Fujiuara, Glenn T., and Kiyoshi Yamaki. 2000. "Trends in Demography of Childhood Poverty and Disability." *Exceptional Children* 66: 187–99.
- Garth, Bryant. 1994. "From Civil Litigation to Private Justice: Legal Practice at War with the Profession and Its Value." 59 *Brook. L. Rev.* 931 (1993–1994).
- Genuis, S.J. and T.P. Bouchard. 2009. "Celiac Disease Presenting as Autism." *Journal of Child Neurology* 25 (1): 114–19.
- Goldberg, Steven S. 1989. "Failure of Legalization in Education: Alternative Dispute Resolution and the Education for All Handicapped Children Act of 1975." 18 *J.L. & Educ.* 441.
- Gould, Elise. 2004. "Decomposing the Effects of Children's Health on Mother's Labor Supply: Is It Time or Money?" *Health Economics* 13 (6): 525–41.
- Hays, Sharon. 1996. *The Cultural Contradictions of Motherhood*. New Haven, CT: Yale University Press.
- Jarbrink, Krister, Eric Fombonne, and Martin Knapp. 2003. "Measuring the Parental, Service and Community Costs of Children with Autistic Spectrum Disorders." *Journal of Autism and Developmental Disorders* 33 (4): 395–402.
- Keane, Michael P. 2010. "Structural vs. Atheoretic Approaches to Econometrics." *Journal of Econometrics*, 156 (1): 3–20.
- Keiser, Lael R. 2006. "Why It Matters Whether State Bureaucrats Opposed to Federal Bureaucrats Administer Federal Programs" in *Politics, Policy and Organizations: Frontiers in Scientific Study of Bureaucracy*, George A. Krause and Kenneth J. Meier (editors), University of Michigan Press, 204–232.
- Kuhlthau, K. A., and J. M. Perrin. 2001. "Child Health Status and Parental Employment." *Archives of Pediatric and Adolescent Medicine* 155, 1346–1350.
- Landsman, Gail Heidi. 2009. *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*. New York: Routledge.
- Lee, A. R., D. L. Ng, J. Sivin, and P.H.R. Green. 2007. "Economic Burden of a Gluten-Free Diet." *Journal of Human Nutrition and Dietetics* 20 (5): 423–30.
- Leiter, V., M.W. Krauss, B. Anderson, and N. Wells. 2004. "The Consequences of Caring: Effects of Mothering a Child with Special Needs." *Journal of Family Issues* 25 (3): 379–403.
- Leonard, Barbara, Janny Dwyer Brust, and James J. Sapienze. 1992. "Financial and Time Costs to Parents of Severely Disabled Children." *Public Health Reports* 107 (3): 302–12.
- Lewis, S., C. Kagan, and P. Heaton. 2000. "Dual Earner Parents with Disabled Children: Patterns for Working and Caring." *Journal of Family Issues* 21: 1031–1060.
- Lilly, Meredith B., Audrey LaPorte, and Peter C. Coyte. 2007. "Labor Market Work and Home Care's Unpaid Caregivers: A Systematic Review of Labor Force Participation Rates, Predictors of Labor Market Withdrawal, and Hours of Work" in *Milbank Quarterly* 85 (4): 641–690.
- Lino, Mark. 2010. "Expenditures on Children by Families, 2009." Report. U.S. Department of Agriculture, Center for Nutrition Policy and Promotion, Miscellaneous Publication, Number 1528–2009.

- Meyers, Marcia K., Henry E. Brady, and Eva Y. Seto. 2000. "Expensive Children in Poor Families: The Intersection of Childhood Disabilities and Welfare." Report. San Francisco: Public Policy Institute of California.
- National Council on Disability 2005. "The Current State of Transportation for People with Disabilities in the United States." Report. Washington, DC: National Council on Disability.
- National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health and Development. 2011. "Down Syndrome." www.nih.gov. Retrieved June 11, 2011. (http://www.nichd.nih.gov/health/topics/down_syndrome.cfm).
- National Organization on Disability. 2004. "N.O.D.-Harris Summary, Key Indicators, Exhibit 2." Report. Washington, DC: National Organization on Disability.
- Newacheck, Paul W., Moira Inkelas, and Sue E. Kim. 2004. "Health Services Use and Health Care Expenditures for Children with Disabilities." *Pediatrics* 114: 79–85.
- New Hampshire Department of Health and Human Services. 2011. "Eligibility—Children Under 19." www.dhhs.state.nh.us. Retrieved June 23, 2011. (<http://www.dhhs.state.nh.us/dfa/medical/children.htm>).
- Parish, Susan L., J.M. Cloud, J. Huh, and A.N. Henning, 2005. "Child Care for Low-income Children with Disabilities: A Population-based Analysis of Cost and Access." *Children and Youth Services Review* 27: 905–918.
- Pearce, Diana. 2008. "The Real Cost of Living in 2008: The Self-Sufficiency Standard for New Jersey." Report. Seattle: The Center for Women's Welfare, University of Washington School of Social Work.
- 2011. "The Self-Sufficiency Standard for Ohio 2011." Report. Seattle: The Center for Women's Welfare, University of Washington School of Social Work.
- Porterfield, Shirley L. 2002. "Work Choices of Mothers in Families with Children with Disabilities." *Journal of Marriage and Family* 64 (4): 972–81.
- Powers, Elizabeth. 2001. "New Estimates of the Impact of Child Disability on Maternal Employment." *American Economic Review* 91 (2): 135–39.
- Rosenbaum, Sara. 2002. "Health Policy Report: Medicaid." *New England Journal of Medicine* 346: 635–640.
- Sacco, Patricia; Gorana Capkun-Niggli; Xin Zhang; and Rosemary Jose. 2013. "The Economic Burden of Fragile X Syndrome: Healthcare Resource Utilization in the United States." *American Health and Drug Benefits*, 6(2):73-83
- Salkever, David S. 1985. "Children's Health Problems and Maternal Work Status." *Journal of Human Resources* 17: 94–109.
- Shattuck, Paul T., Susan L. Parish. 2008. "Financial Burden in Families of Children with Special Health Care Needs: Variability Among States." *Pediatrics*, 122 (13): 13–70.
- Shearn, Julia and Stuart Todd. 2000. "Maternal Employment and Family Responsibilities: the Perspectives of Mothers of Children with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 13: 109–131.
- Silberstein, A. R., and S. Scott. 1991. "Expenditure Diary Surveys and Their Associated Errors." in P. P. Biemer, R. M. Groves, L. Lyberg, N. A. Mathiowetz & S. Sudman (editors), *Measurement Errors in Surveys*. New York: John Wiley and Sons.
- Silver, Charles. 2002. "Does Civil Justice Cost Too Much?" 80 Tex. L. Rev. 2073 (2001–02).
- Silver, E. J., and REK Stein. 2001. "Access to Care, Unmet Health Needs, and Poverty Status Among Children with and without Chronic Conditions." *Ambulatory Pediatrics* 1: 314–320.

- Smith, Noel, Sue Middleton, Kate Ashton-Brooks, Lynne Cox, and Barbara Dobson, with Lorna Reith. 2004. "Disabled People's Costs of Living: More Than You Would Think." Report. Joseph Rowntree Foundation, University of Loughborough.
- Sousa, Amy C. 2011. "From Refrigerator Mothers to Warrior-Heroes: The Cultural Identity Transformation of Mothers Raising Children with Intellectual Disabilities." *Symbolic Interaction*, 34 (2): 220–243.
- Sousa, Amy C. 2015. "'Crying Doesn't Work': Emotion and Parental Involvement of Working Class Mothers Raising Children with Developmental Disabilities." *Disability Studies Quarterly* 35: 1 (2015), <http://dsq-sds.org/article/view/3966/3834>.
- U.S. Bureau of the Census. 2010. "Income, Poverty, and Health Insurance Coverage in the United States: 2009." Report. Washington, DC: Bureau of the Census. 60–238.
- U.S. Bureau of the Census. 2013. "Current Population Survey, 2013. Annual Social and Economic (ASEC) Supplement." Report. Washington, DC: Bureau of the Census. i–330.
- U.S. Bureau of the Census. 2014. "Measuring America: How Census Measures Poverty." Report. Washington, DC: Bureau of the Census.
http://www.census.gov/library/infographics/poverty_measure-how.html
- U.S. Government Accountability Office. 2005. "Federal Disability Assistance: Wide Array of Programs Needs to be Examined in Light of 21st Century Challenges." Report. GAO-05-626. Washington, DC: U.S. Government Accountability Office.
- U.S. Internal Revenue Service. 2011. "Publication 502: Medical and Dental Expenses." Report. Cat No. 15002Q. Washington, DC: U.S. Department of the Treasury. March 3.
- U.S. Social Security Administration. 2011. "Understanding Supplemental Security Income (SSI) for Children: 2011 Edition." www.ssa.gov. Retrieved on March 7, 2011. (<http://www.ssa.gov/ssi/text-child-ussi.htm>).
- Wider Opportunities for Women. 2011. "The Self-Sufficiency Standard." [WOWonline.org](http://www.wowonline.org). Retrieved January 5, 2011 (<http://www.wowonline.org/ourprograms/fess/sss.asp>).

ⁱ The material cost was calculated using US Labor price index of raw ingredients for the simplest gluten-free bread recipe available through a Google search. The recipe also called for one hour of time; using the Self-Sufficiency Wage for Boston in 2003, this cost came to \$24.66. The total of the materials and labor was divided by four, which assumes that four loaves are made simultaneously for efficiency and cost reduction.

ⁱⁱ See Table 1