

Appendix I: RCL Adjustments for People with Disabilities

How much income is needed to meet basic needs if you have a disability? Building from experience calculating New Jersey's RCL, this section explores some of the issues in estimating the extra costs associated with disabilities and makes some estimates of what those costs may be. By understanding more about the costs associated with disabilities, we hope to shed light on the policies and approaches that impact families with disabilities and the need for further research on the cost of disabilities.

The RCL provides a refined and detailed answer to the question of what it takes for individuals and families to be economically self-sufficient, taking account of where they live, the number of adults and children in a household, and the ages of the children. Costs are calculated according to minimal standards for a modest but decent standard of living. The RCL does presume that a given amount of resources will translate into a given level of well-being for all families of a given composition, in a given place.ⁱ For example, it is assumed that a set amount of funds (determined by household composition) will provide sufficiently nutritious meals for all members of the specified family. Yet, for people with disabilities, this may not be the case. It may be that the cost of a nutritionally adequate diet is higher for someone with a disability if special diets or preparation is required. In addition, implicit in the RCL measure is the assumption that this level of resources only meets basic needs at adequate levels, but also enables adults and children to participate in society—adults to be employed, children to attend school, and all to be safely housed and transported as required. The RCL presented in previous sections of this report may well fall below what is needed for a basic level of income adequacy for those with disabilities. The research summarized in this section estimates by how much.

For people with disabilities, there are additional costs to attain an equivalent level of both meeting basic needs and participating in what one author termed “an ordinary life”.ⁱⁱ There are three types of costs associated with having a disability. First, there are higher costs associated with basic expenses, such as food and shelter. For example, wheelchair accessibility may increase the cost of housing. Second, there are needs specific to disabilities for items and services, such as Braille readers and personal attendants. Even relatively mundane items, such as a can opener, can be more expensive for those with disabilities, while a manual can opener may be sufficient for most, and an electric can opener may be required for some with disabilities. Finally, there are costs associated with removing barriers to participation in employment and social life of the community, such as specialized transportation or communication devices.

Clearly, the basic RCL is not enough to meet the costs associated with many disabilities. How much should be added, however, and how should such costs be calculated in order that persons with disabilities may achieve an equivalent standard of living?

This section outlines some of the issues involved in estimating the extra costs associated with disabilities, and makes some estimates of what those costs may be. It should be emphasized, however, that these estimates are just that, estimates, and are far from definitive, as there is very little data, and little consensus on methodology. In addition, since there is no known study in the American context of these costs, the following analysis draws from research done in similar Western societies (Ireland, the United Kingdom, Australia, and New Zealand). While similar in many ways, these societies have quite different policy environments regarding support and services of people with disabilities (particularly health care).ⁱⁱⁱ Given these caveats, it is hoped that these estimates will stimulate further research and discussion, as a first step toward better understanding the costs of disability.

FACTORS AFFECTING THE MEASUREMENT OF DISABILITY-RELATED COSTS

There is wide variation in disabilities and associated costs vary based on different factors. In order to estimate the extra costs associated with having a disability, several attributes must be taken into account. These include:

Severity and Type of Disability: Disability-related costs vary greatly depending on number, type, and severity of disabilities. While some researchers estimating disability-related costs have used a severity index,^{iv} others have estimated costs on the basis of various sets of needs, rather than impairments.^v Some types of impairment incur more costs than others. For example, one study found that costs associated with disabilities in the areas of dexterity/reaching and locomotion were higher than for those related to incontinence or seeing/hearing.^{vi}

Current vs. Long-term Expenditures: As with most cost of living budgets, the RCL is intended to account for current costs, and does not include past or future investments. Thus, for example, it includes the cost of rent, but not the deposits often required to secure housing. In contrast, studies of disability-related costs often include the cost of purchasing or replacing adaptive equipment such as wheelchairs, cars with lifts, and communication devices.

Living Arrangements: Whether an individual with a disability lives alone, with others who do not have disabilities, or with a partner, who has disabilities, affects cost of living estimates. In this report, costs for people with disabilities are modeled according to different living arrangements. Costs have been found to be lower for couples in which one person has a disability, compared to costs for a single person with a disability or couples in which both partners have disabilities. It is hypothesized that the second adult in these

households substitutes some unpaid care services for disability-related needs that would otherwise generate additional costs. For this reason, some researchers have concentrated on estimating costs for a single person, living alone, so as not to inadvertently underestimate disability-related costs because others have mitigated them in the household or the household budget in general.

Work Status: The Standard assumes that all adults are working, full-time, and therefore incur the costs associated with working. While housing and food costs within the basic RCL are not calculated taking work status into account, transportation to and from work, childcare if needed, and taxes from earned income are calculated with the assumption of full-time work status for all adults in a household. However, among people with disabilities, full-time work is not necessarily the norm within a range of work statuses from not working at all to working full-time. If the comparison were to be between, for example a single person working full-time, and a single person with disabilities not working at all, it would be an “apples and oranges” comparison because of the different circumstances, income source, and costs for those working versus not working, and the differences could be attributable to either disabilities, or contrasting work statuses, or some combination, without any way to separate out such differences. Instead, by assuming that people with disabilities also work and therefore have the costs associated with work, the extra costs associated with disabilities can be determined.

Public Resources and Supports: The public resources available in a community or from the government affect individual disability-related costs, as they may reduce the amount individuals and families must expend. For example, the presence of curb cuts and special accessible public transportation can affect mobility greatly, and reduce the amount that individuals may have to expend to achieve an adequate level of mobility. Moreover, these kinds of resources vary significantly from one place to another. Unfortunately, there is no data currently available to assess accurately the extent or variability of this component of costs, and none of the studies utilized here explicitly addresses this issue.

MEASURING DISABILITY-RELATED COSTS

Ideally, as with all RCL costs, disability-related cost estimates would be based on direct measures of specific costs, both higher costs for general basic needs such as food and shelter, as well as costs that are specific to a disability. Unfortunately, detailed, comprehensive, and standardized data for specific disability-related costs are not available, in the United States. Nor are there government-set cost estimates that are disability-specific such as those established by the Department of Agriculture for food budgets intended to meet minimum nutritional standards. Because disability benefits are set at the same level statewide or even nationally, and bear no relation to actual costs but rather reflect public budget or political concerns, the level of disability benefits is not an indicator of actual costs.^{vii}

Given the lack of cost-specific data, there are two approaches to measuring disability-related costs. The first is the direct approach in which the extra costs associated with disability are itemized and costed out specifically. This direct approach can be done using research methods that include expenditure surveys, diaries, or creating a budget in which it is determined what individuals with disabilities need, and then pricing this item list. Smith, et al. used the latter method with the direct approach, having focus groups of disabled persons estimate both the general and the disability-specific needs of five case study individuals, reflecting five different clusters of disability-related needs.^{viii} Resulting expenditure lists were checked by another set of focus groups, priced independently, and then compared to the average costs for the needs of a person without a disability. Although approximately four out of five persons with disabilities do not live alone, Smith et al. decided to develop costs for a single person in order not to inadvertently incorporate the hidden subsidies of other household members providing services or care (costs for persons with disabilities who are living with non-disabled persons have lower costs, suggesting that there are some private subsidies that reduce costs over those of someone with disabilities living alone). Similarly, Indecon (2004) in Ireland used expenditure diaries to document disability-related expenditures as well as standard expenditures.^{ix} Whichever method is used as part of the direct approach, the result avoids the problem of income constraints artificially lowering cost estimates.

Given that people with disabilities consistently have lower incomes and higher levels of poverty,^x addressing this problem is important. At the same time, by involving the disabled themselves, the direct approach reflects more closely, what this community deems as needs, including items that help address barriers to participation in the larger community, thus moving away from a more narrowly defined and medicalized definition of disability and its associated needs/costs.^{xi}

A second approach addresses these issues by taking an indirect approach. Using a set of consumer durables/purchases that range from a refrigerator to “taking a vacation”, a scale of living standards is created. Then using surveys, expenditures of households with a person with disabilities are compared to expenditures of comparable households in which there is no one with disabilities, controlling for the standard of living. The difference is assumed to be the “cost” of disability without specifying the actual expenditures. However, given the problem that households with persons with disabilities have lower incomes on average, as stated above, disability-related expenditures may be less than they should be, as some of these households do not have adequate income to meet all their needs, whether disability-related or not. To control for the impact of associated income constraints, researchers use data from across the income spectrum, and statistically control for not only income level, but also other factors that affect expenditure levels, such as gender and housing tenure.

Researchers using this approach distinguish between levels of severity of disability. Zaida and Burchardt differentiated among households with a person with a disability by using a

severity of disability index that ranges from 0 to 22, determining the average additional expenditure associated with each point on this scale.^{xii} For non-retired individuals and couples at an average income level, approximately 4 percent to 4.6 percent additional expenditure is associated with each point on this disability severity scale. For example, a single, non-retired person with a low severity of disability (score 3), would incur additional disability-related expenses of 14 percent on average; at the medium severity level (score 9), disability costs would increase the budget by 41 percent; and at the high severity level (score 17), disability-related costs would result in expenses increasing by 78 percent.

To illustrate the impact of disability-related costs on economic self-sufficiency, we have used findings from both the direct and indirect approaches to estimate the costs for different levels or types of disability. Estimates based on Smith et al.'s study use the five types of disability described in that study. Estimates based on Zaidi and Burchardt's research use the three levels of disability severity as described above (low, medium, and high), for three different household composition/disability combinations. We also use estimates based on a study by Cullinan et al. (2008)^{xiii} which extends previous research methods such as those of Zaidi and Burchardt with the three levels of disability used in that study, differentiated by severity into three groups: disabled with severe limitations, disabled with some limitations, and disabled with no limitations. To apply these findings to the situation facing persons with disabilities in New Jersey, we start with the RCL for a single adult and for two adults in Mercer County. Although not all individuals with disabilities are employed, or receive all of their income from earnings, as stated above we have maintained the assumption from the basic RCL that all income is earned by someone in the household. This makes these numbers comparable, so that we can estimate the costs of disability for individuals in New Jersey, other things being equal, including work status. Because additional costs require earning additional income to cover them, taxes increase as costs rise.

As can be seen from Table 1, disability-related needs increase costs at varying rates, depending upon the source, the severity of disability, and household composition.^{xiv} As one would expect, costs clearly increase as the severity of disability increases, regardless of the method used to estimate those costs. Across estimates using the three study methodologies in Table 1, for those with the highest level of severity (high or severe limitations), the estimates range from 44 percent to 107 percent of income needed to meet the non-disability accounted RCL due to additional disability related costs. For those with medium (medium severity, low medium, or hampered to some extent), costs range from 23 percent to 41 percent. For those with low, the range is from 9 percent to 14 percent. For those with "intermittent", hearing, or vision impairment, which were only estimated by Smith et al, the estimates are 42 percent, 46 percent and 47 percent.

When these estimates are applied to the example of Mercer County households, the cost of disability is clearly substantial, particularly for those higher on the severity index. Thus, the single, nondisabled person living in Mercer County needs to earn at least \$2,394 per month

but, if this person has a disability, he or she needs to earn from \$2,631 to \$5,743 per month, depending on the severity of the disability and the estimate percentage used. Note that the costs for those with more severe disabilities are estimated to be higher in the Smith study, due to the methodology used. High as some of these cost estimates are, they are likely to be substantial underestimations for several reasons:

- These estimates are based on studies from the United Kingdom, Ireland, and New Zealand, where there is substantially more public subsidy of some costs, especially health care and, for a substantial number, housing. Thus, some of the additional costs associated with disability, such as special housing or additional health care services, are more likely to be covered for those with disabilities in these countries than in the United States.
- The RCL takes into account the cost of obtaining private health insurance. Private coverage, however, is insufficient to meet the needs of many people with disabilities. It generally does not cover personal care attendant costs, and often limits coverage of pre-existing conditions or schedules higher premiums for people with higher actuarial risk. Until recently, if a person with disabilities entered employment, they automatically lost their eligibility for Medicaid and faced a difficult choice of being employed, but underinsured, or unemployed, but insured (through Medicaid). However, as provisions of the Affordable Care Act expand coverage, through expanded Medicaid, health exchanges, and/or employer-provided health care, this may lessen this difficult choice facing persons with disabilities.^{xv}
- The methodologies used assume that costs associated with disability are fixed, and do not change with income.^{xvi} These estimates do not take account the time costs. In some instances, disabilities may require longer time for daily living activities, such as eating and transportation, which can then decrease the amount of time spent in paid employment.
- Costs, such as initial investment in equipment, or adaptation, are included in these estimates to some (but unknown) degree. Some of these investments may be essential to personal mobility and social interaction.

Table 1: Disability Related Costs of Living per Household, by Disability Level/Type and Living Arrangements, for Households in Mercer County, 2011

Level of Disability	Single Adult		Couple, One Disabled		Couple, Both Disabled	
	Percentage Increase for Disability Related Costs	Total Costs, Including Disability Related Costs	Percentage Increase for Disability Related Costs	Total Costs, Including Disability Related Costs	Percentage Increase for Disability Related Costs	Total Costs, Including Disability Related Costs
No Disability	0%	\$2,394	0%	\$3,435	0%	\$3,435
With Disability						
Based on Zaidi & Burchardt (2003)*						
Low Severity (score 3)	14%	\$2,784	13%	\$3,971	24%	\$4,420
Medium Severity (score 9)	41%	\$3,537	39%	\$5,039	72%	\$6,412
High Severity (score 17)	78%	\$4,755	73%	\$6,454	136%	\$9,428
Based on Noel Smith et al (2004)**						
Low -Medium Needs		34%		\$3,337		
Medium-High Needs		107%		\$5,743		
Intermittent Needs		42%		\$3,565		
Needs Related to Hearing Impairment		47%		\$3,708		
Needs Related to Vision Impairment		46%		\$3,679		
Based on Cullinan (2008)***						
Disabled though <i>not hampered</i> in daily activities		9%		\$2,631		
Disabled and <i>hampered to some extent</i> in daily activities		23%		\$3,026		
Disabled and <i>severely hampered</i> in daily activities		44%		\$3,633		

Source: * Zaidi & Burchardt, "Comparing Incomes When Needs Differ: Equivalisation for the extra costs of disability in the UK," Feb 2003. (See text for explanation of methodology and detailed findings.)

** Noel Smith, 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" Joseph Rowntree Foundation, University of Loughborough.

*** Cullinan, John, Brenda Gannon, and Sean Lyons. Estimating the Economic Cost of Disability in Ireland. Working Paper Series #230, Dublin: Economic and Social Research Institute, 2008.

Even with these important reservations, it is clear that, for people with disabilities to achieve minimally adequate income and resources, substantially more is required than the amount needed for the basic RCL.

Children with Disabilities

All of the above estimates are for adults with disabilities. The costs for children with disabilities would be similar in some ways, but unfortunately, none of the studies reviewed have addressed these issues, so we are limited to simply outlining some of the conceptual and methodological issues involved.^{xvii}

Owing to multiple factors, such as environmental exposures and limited access to health care, children in families with low incomes have been found to have a higher likelihood of being disabled.^{xviii} At the same time, families with lower incomes, by definition, have fewer resources to meet the increased costs of children with disabilities as they struggle to achieve enough income to meet their basic needs. As a result, families with a child or children with disabilities may experience greater economic hardship than families whose children do not have disabilities even at similar income levels and family compositions.

There would be several types of disability-associated costs that would need to be taken into account in estimating costs for a family with one or more children with disabilities.

One of the most important, and often the largest costs would be the “opportunity” cost that could limit at least one adult in the family from participating fully in the workforce. Other parents may be constricted from undertaking paid work at all. Workforce limitations could be due to the need for adults to take children to medical and therapy appointments, difficulties with children being able to be at home or outside on their own, help with daily living tasks, preparation of special diets, and/or difficulties in obtaining suitable respite or day care that meets a disabled child’s needs. Several past studies have found that parents (and particularly mothers) of special needs children are much less likely to participate in the workforce than parents of children without special needs. Furthermore, as the severity and number of children with disabilities increase, so does the impact on participation in the workforce.^{xix}

- Disability-related increased costs of food, transportation, and so forth may be similar to that of adults, although more research is needed. As with adults, out-of-pocket expenses increase with the severity of the disability condition. In the 1997 study, “The Cost of Caring: Childhood Disability and Poor Families” researchers found that about half of families with children with any special needs incurred increased expenses for special services such as transportation and food.^{xx} This study found that nearly 40 percent of families with one child with a mild or moderate condition incurred some out-of-pocket expenses within the last month. Likewise, 57 percent of families with more than one

child with any severe condition incurred out-of-pocket expenses in the last month. Disability-specific costs may be similar to that of an adult, but childcare may be considerably more expensive, again depending upon the type and severity of disability, and the child's age.

- Finally, school age children with disabilities receive some goods and services in connection with their public education such as occupational, speech, or physical therapy, or are otherwise covered categorically, that is, coverage is not income-related. However, mandated Individual Education Plans (IEPs) for students with disabilities may require substantial parental participation, both in developing the plans, and overseeing their implementation, and coordinating school-related and other services.
- As with adults with disabilities, there is an uneven coverage of needs. Public benefits are income-based (except education), so any assessment of costs for children with disabilities would have to take into account eligibility for means-tested and non means-tested benefits. Although for adults who do not have disabilities, the income levels required for self-sufficiency virtually always make a family ineligible for means-tested programs such as Medicaid, persons with disabilities, particularly children, may be eligible for some types of assistance at higher incomes or regardless of income. Thus children, including those with disabilities, may be eligible for the Children's Health Insurance Program (CHIP) coverage when adults would not be. At the same time, restriction of eligibility criteria of children for programs such as Supplemental Security Income (SSI) limits available support for children with disabilities.

When income is below the level needed for economic self-sufficiency, families and individuals are often faced with difficult household budget decisions. Disability-related costs are likely to affect families with a disabled child at higher income levels than those of the basic RCL. Further research is needed to determine the income adequacy levels necessary to meet the needs of both children and adults with disabilities.

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i. (Sen 1993) see also (Kuklys 2004).

ii. (Wilkinson-Meyers, et al. 2010).

iii. Despite extensive searching, no comparable work has been found for the United States. There has been extensive work on the medical costs associated with various disabilities, but no analysis could be found on the living costs associated with disability.

iv. (Zaidi and Burchardt 2005).

v. (Smith, et al. 2004).

vi. (Zaidi and Burchardt 2005).

vii. Eligibility for and levels of disability-related government benefits are often surprisingly disconnected from a person's need for assistance. A person with a severe physical disability, for example, may be ineligible for assistance to pay for expensive devices that would improve his or her ability to function independently at home. If the disability began prior to age 18, however, an individual may be eligible for assistance through the Division of Developmental Disability. Similarly, people with all types and levels of disability generally receive the same level of benefit as Supplemental Security Income recipients. The lone exception is the larger amount received by blind or visually impaired people.

viii. (Smith, et al. 2004).

ix. (Indecon International Economic Consultants 2004).

x. (Saunders 2007, 20).

xi. (Wilkinson-Meyers, et al. 2010, 8).

xii. The index used was the OPCS severity scale of disability, described by the authors as the "gold standard" in the UK for measuring disability severity in non-medical settings. For further discussion, see (Zaidi and Burchardt 2005, 11 and Appendix 1) as well as (Martin, Meltzer and Elliot 1988). For a discussion of the International Classification of Functioning, Disability and Health (ICF), the classification system agreed to by the World Health Organization in 2001, see <http://www.cdc.gov/nchs/about/otheract/icd9/icfhome.htm>.

xiii. Note that two articles by Cullinan and associates were consulted: (Cullinan, Gannon and Lyons, Estimating the Economic Cost of Disability in Ireland 2008) and (Cullinan, Gannon and Lyons 2011). Both reported analysis of the 1995-2001 LII (Living in Ireland) datasets, and used very similar approaches. However, the results were reported somewhat differently, leading to slightly different numbers. The earlier study was chosen to be used here for two main reasons: (1) the (2008) study reported on the different costs for pensioners vs. non-pensioners, allowing for a calculation of the numbers for non-pensioners, thus making it possible to make the Cullinan estimates numbers comparable to Zaida and Burchardt 2005 and Smith, et al. 2004, which were based on costs for non-pensioners. (Note that costs are lower for pensioners in the Irish context, which the authors suggest may reflect reduced medical costs to the pensioner; it may also reflect reduced work-related costs.) (2) The latter article (2011) includes an attempt at analyzing the "short-term" and "long-term" costs of disability, in an attempt to capture the fact that there is some movement in and out of disability status, as well as between levels of disability. The results were problematic, as both the definition and explanation of short and long term were not clear, and the findings were mixed and inconsistent by level of severity. Again, since the other sources used did not distinguish between "short-term" and "long-term" costs, but did distinguish by level of severity, the 2008 study provides a better source of comparable estimates of the cost of disability.

xiv. Note that, for two adult households in which both partners have disabilities the disability-related costs are doubled, as this is how the marginal costs were calculated in the Zaidi and Burchardt 2005 monograph.

xv. The NJ WorkAbility Program, New Jersey State's program created under auspices of the Federal Ticket to Work Act of 1999, offers full New Jersey Medicaid health coverage to working permanently disabled individuals whose earnings level would otherwise make them ineligible for Medicaid. The income eligibility level for NJ WorkAbility is yearly earned income of no more than \$54,948 for an individual and \$73,644 for couples (both with a permanent disability and both working). While this greatly mitigates the problem of losing essential Medicaid coverage, it is not entirely alleviated. We estimate, for example, that a severely disabled person in Mercer County may require more than \$4,755 monthly to be self-sufficient. This is just an estimate, however, and it is likely that some individuals may have particular needs that would lead to even greater disability-related expenses than what would be typical for a severely disabled person. Our estimate of self-sufficiency at \$4,755 per month for an individual with a severe disability exceeds NJ Workability's income eligibility limits for Medicaid coverage. If the individual required \$2,500 in monthly personal care attendant services, then her individually "adjusted" self-sufficiency standard would be over \$7,200. State of New Jersey, Department of Human Services, Division of Disability Services, "DiscoverAbility/NJ WorkAbility," <http://www.state.nj.us/humanservices/dds/projects/discoverability/> (accessed August 12, 2011).

xvi. (Zaidi and Burchardt 2005)

xvii. (Middleton, Ashworth and Braithwaite 1997)

xviii. (Meyers, Lukemeyer and Smeeding 1998, 219) Twelve percent of children had disabilities in families who were current or recent welfare recipients according to the California AFDC Household Survey. Six percent of children in the general population had disabilities in the 1996 National Health Interview Survey.

xix. (Lukemeyer, Meyers and Smeeding 2000) Only 29% of mothers of chronically ill or disabled children, and only 19% of mothers of severely disabled children were in the workforce, compared to 39% of mothers of healthy children.

xx. (Meyers, Lukemeyer and Smeeding 1998).