



## RESEARCH BRIEF #34

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### Physical Health Impacts of Grandparenting Children with Disabilities

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Nearly 17% of U.S. children have developmental disabilities, and the rates are rising.<sup>1</sup> Given the shortage of childcare options, many families turn to grandparents. American grandparents provide more grandchild care than grandparents in most industrialized nations.<sup>2,3,4</sup> Millions of grandparents are quietly, almost invisibly, providing vital care for their grandchildren with disabilities, ranging from feeding, dressing, and bathing, to helping with homework, administering medications and therapies, and hooking up feeding tubes. Neither the U.S. government nor employers have expanded benefits for working families. While some grandparents have sufficient resources and few enough demands, to juggle caring for grandchildren with disabilities seamlessly, those who are providing the most intense care with the fewest resources are more likely to experience adverse physical health effects. Federal recognition and support of grandparent care work would assure more comprehensive care, more equitable distribution of resources, and an improvement in grandparent wellbeing.

This brief summarizes a chapter from our recently published book, *Grandparenting Children with Disabilities*, in which we conducted in-depth interviews with 50 grandparents who care for their grandchildren with disabilities.<sup>5</sup> We assessed the wide array of care work they provide and its impact on their physical wellbeing. Many grandparents experience a mix of both positive and negative effects. Care work for grandchildren often results in better diets and more exercise, but these benefits may often be negated by insufficient rest, relaxation, days off, doctor visits, and dental care.

#### KEY FINDINGS

- Although caring for grandchildren with disabilities often brings substantial joy to grandparents, it can adversely impact grandparents' physical health.
- For many grandparents, caring for their grandchildren makes them feel younger, mostly because they are more physically active and maintain healthier diets.
- For some grandparents, repetitive activities like bending and lifting, or providing constant supervision of grandchildren, take a physical toll, especially if these individuals are unable to take time off from their care work for rest, doctor visits, or dental care.
- To relieve pressure on grandparents, federal and state policymakers should expand childcare supports for working families.

## Positive Health Impacts

Many of the grandparents we interviewed said the activities they do to provide care for their grandchildren with disabilities have improved or helped sustain their overall level of fitness and physical wellbeing. Chasing a toddler across the backyard, walking a child home from the bus stop, and carrying a grandchild upstairs for a bath are all activities that provide exercise. Whether they have always prioritized exercise or have increased their physical activity due to care work, many say it supports their health and keeps them feeling younger.

Taking grandchildren on outings keeps many grandparents physically active and feeling younger. Paul, age 69, cares for his six-year-old grandson with Down syndrome, Alex, every three weeks and invites his other two grandchildren to come to stay with him and his wife as well. Paul rates his health as good. He feels that caring for Alex has positively impacted his health because he makes a point to keep a very active schedule when they are together. Paul takes Alex everywhere. Paul stated, “We go camping. We pick apples. We go hiking. We go swimming. Everything. They make me feel young.” One of the symptoms of Down syndrome is low muscle tone. Paul spends quite a bit of time swimming and doing other activities to improve Alex’s muscle tone. When Alex was little, Paul used to carry him a lot, which kept Paul fit. Now that he is older, they are working on riding a bicycle. Paul detailed, “He no longer needs us to pick him up because his tone has definitely increased. I’m teaching him now how to ride a two-wheeled bike.”

**Paul, 69, shares the positive outcomes of caring for Alex, his six-year-old grandson who has Down syndrome, stating that it keeps him active and feeling healthy.**

Some grandparents make sure they get enough exercise by taking their grandchildren with disabilities with them when they work out. Joyce is a 61-year-old, white retiree who attended some college and has one grandchild, 13-year-old Mindy, who lives with her. Mindy’s mother was declared unfit, and her father has custody, but Joyce and her husband care for Mindy around-the-clock. Mindy has DiGeorge syndrome. Joyce is happy to include Mindy in some of her exercise routines. Though Joyce has had some serious health problems, she goes to the gym at least twice a week and rates her health as good. Sometimes, she brings Mindy with her to the gym. She recalled, “When she’s not at school, she goes with me. It’s an exercise class for people over 50. And, they actually love her. She’s made a lot of friends there. And, she does it too.” Joyce tries to schedule her medical appointments for times when Mindy is at school, though sometimes she brings her along on these outings as well.

## Negative Health Impacts

While a few grandparents said that caring for grandchildren with disabilities had no impact on their physical health, many have shared fairly adverse health consequences. Several have major health issues and find that it is particularly challenging to provide care work. Others have stated that it is the care work itself that is negatively impacting their physical health. Often there is too much chasing, bending, and lifting for their aging bodies. For those who are providing custodial care, there is rarely a break for exercise or rest. Even if they appreciate that the additional physical activity is beneficial, many are simply too exhausted and too busy to care properly for their own health. Some are delaying visits to the doctor and dentist, surgeries, and other needed medical care.

**Donna, 63, has adopted two of her grandchildren with disabilities and provides around-the-clock care to meet their needs. Her health, particularly her Lupus, has worsened due to inadequate support.**

Some grandparents with chronic conditions find that providing care for grandchildren with disabilities day after day, and year after year, impairs their health and wellbeing. Donna is a 63-year-old, white, retired social worker and a married mother of three biological children and two adopted grandchildren. Donna’s middle son has a substance abuse problem. He has four children who have lived in foster homes. Donna and her husband petitioned Child Protective Services to obtain custody of two of the children, at the ages of four

and three. Sally, now age 11, has been diagnosed with adjustment disorder and ADHD. Tony, now age 10, has also been diagnosed with ADHD. Donna was enjoying being an empty nester and working full time, but when they gained custody of the children, she retired and became a stay-at-home grandmother. Now Donna provides around-the-clock care. She had to get reacquainted with raising children. Raising these young children is emotionally and physically exhausting for Donna. She stated, “My health has taken a toll; I have Lupus. Lupus is a disease that is exaggerated by stress so this is not good for my Lupus.”

Similarly, Marina, age 60, continues to work part-time and to commute 25 minutes to care for her two-year-old granddaughter Carly, who has Williams syndrome. She is the bookkeeper for the family business and works 15-20 hours per week, so her time is flexible enough to care for Carly and the rest of her five grandchildren. For a while, she watched one granddaughter five days a week, another two days a week, and a grandson two days a week. Marina has had several significant health problems, and her intensive play with Carly takes a toll. Marina lamented,

*“Physically, it drains me. I’m not a spring chicken anymore. It is tiring. I have to be to bed by 9 p.m. I can’t handle anything later than that. I have had knee replacements and spinal fusion but I still get on the floor and play with her, and do backward rolls. I do what I have to do and I do get tired. I find it very rewarding watching her and seeing her grasp something I’m trying to teach her. How delighted she is. It truly is rewarding.”*

### **State and Federal Governments Must be More Supportive of Working Families**

Grandparents often need more support as they divert much of their money, time, and energy to care for grandchildren with disabilities. Those who provide the most care with the fewest resources are more likely to contribute more funds than they can afford, retire early, and neglect their own physical health by foregoing exercise, proper nutrition, and medical and dental care. They need more support than they are getting. Respondents requested many forms of support, including stable and expansive social welfare programs, support groups for grandparent care workers, enriching and accessible social programs, and high-quality, affordable childcare for their grandchildren with disabilities. Developing these resources would assist those who need it most: grandparents with the fewest resources who are providing more intensive care for their grandchildren with disabilities.

### **Access to Social Welfare Programs**

The expenses necessary to provide families with children with disabilities the care they need can be enormous. Families with comprehensive health insurance, tremendous resources, and less severe medical issues may be able to manage these costs. But families with fewer resources, little or no health insurance coverage, and more severe diagnoses can be overwhelmed. They need assistance covering household expenses, including food and medical care. The safety net for children with disabilities in the U.S. consists primarily of income-based programs such as Medicaid and SNAP.<sup>6</sup> Eligibility rules, and benefit structures for these programs vary dramatically by geographical location. Many qualified families are not able to secure and retain benefits over time. Families often rely on grandparents to fill in gaps left by the state.

**The scarcity of childcare resources available to American working families and grandparents negatively impacts all involved, taking a toll on grandparent physical health, mental wellbeing, and financial stability.**

### **Easier Access to In-Person and Online Support Groups**

Having access to in-person and online support groups was pivotal for many of the grandparents we interviewed. These groups can help grandparents cope. Unfortunately, this type of social and emotional support for grandparents tends to vary by location and may not be offered consistently. In some areas, such support groups are plentiful while in others, they are nonexistent.

## Enriching, Accessible Social Programs and Affordable Quality Daycare

There are not many social programs for children with disabilities, and grandparents are fervent in their wish for an expansion of this resource. Many had no opportunities for special social events or even accessible playgrounds for their grandchildren. When these options were available, eligibility was often limited and many were left wishing for greater access for all. The lack of flexible, affordable, high-quality childcare is also problematic for many families, particularly when children have disabilities and need more specialized care. American parents are working more than ever, and more than people in other countries.<sup>7</sup> Childcare is often difficult to find, inflexible, expensive, and of variable quality.<sup>8</sup> Given the dearth of childcare options, many families turn to grandparents. Federal policies are needed to guarantee childcare for working families and to address the extensive care work provided by grandparents.

## Looking Forward

Because of the shortage of welfare state programs to support working families, U.S. grandparents are already providing more care for grandchildren than in many other countries. Given that childhood disability rates in the U.S. are rising but supports for working families are not, we expect this trend to continue. Grandparents provide a wide array of care over long periods of time for their grandchildren with disabilities. While spending time caring for grandchildren provides a great deal of joy, it can also adversely affect grandparent health. Grandparents with good health, plentiful resources, and relatively light care work demands often experience generally positive health impacts. However, those with underlying health conditions, fewer resources, and greater care demands are more likely to report tiredness, aches and pains, and neglecting their own health.

If U.S. families enjoyed the broad support that is available in many other developed nations, including federally-guaranteed paid vacations, sick days, parental leave, and health insurance, they would be able to rely less on grandparents. Additionally, if U.S. income-based welfare programs were more expansive and stable, families and grandparents could provide better, consistent long-term care for children with disabilities. Support groups, accessible parks and social programs, and affordable, high-quality child care would allow grandparents to enjoy caring for their grandchildren with fewer negative health consequences.

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