RESEARCH ARTICLE

Disparities in Community-Based Resources for Grandparents Raising Children with Autism Spectrum Disorder: A Call for International Health Surveillance and Advocacy

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ABSTRACT

Despite estimates that one percent of children, worldwide, have a diagnosis of Autism Spectrum Disorder, with prevalence rates as high as three percent of children in the US., coupled with increasing numbers of grandparents who are raising their grandchildren, either as custodial or non-custodial caregivers, limited information is available regarding the essential, community-based, autism spectrum-related services that these grandfamilies need. What we do know is that grandfamilies with children with Autism Spectrum Disorder in different nations, and among different states in the U.S., face significant disparities in the availability of community-based services, influenced in large part by public policies and stigma. This editorial reviews the available information regarding such disparities, and calls for international health surveillance in data collection and advocacy in service of changes in public policy designed to assist these grandfamilies, who serve as an essential societal safety set for many children with Autism Spectrum Disorder.

Keywords: Custodial grandparent, grandfamilies, ASD, Autism, Editorial

Introduction

The World Health Organization estimates that 1 in 100 children, worldwide, have a formal diagnosis of Autism Spectrum Disorder (ASD),1 with the Centers for Disease Control and Prevention (CDC) reporting that 1 in 31 children in the U.S are diagnosed with ASD2. And with the U.S. Census Bureau reporting that 2.1 million custodial grandparents provide primary care for 2.74 million grandchildren in the U.S.,³ one can infer that more than 67,000 of those custodial grandparents care for at least one child with ASD. Additional Census Bureau findings indicate that more than 4 million U.S. grandparents provide primary care for more than 7 million children in grandparent-maintained households.3 Based upon the CDC's aforementioned prevalence rate of ASD,2 it is reasonable to infer that more than 134,000 U.S. grandparents provide primary care for at least one grandchild with ASD, whether they are recognized as that child's official, legal guardian or not. Due to limited data from international health surveillance, even less is known about the numbers of custodial and non-custodial grandparents, worldwide, raising grandchildren with ASD. Accounting for and understanding the communitybased needs of grandparents who are raising a grandchild with ASD is essential, as these grandparents typically provide a vital social safety net that prevents those children from entering foster, or other institutional systems, of care.4

Though we have limited information regarding the actual number of custodial grandparents caring for children with ASD internationally, clear, consistent findings in the literature purport that these essential caregivers face significant challenges and needs, which can vary by both grandparents' (e.g., age, gender, disability status, financial status, culture)4 and their grandchildren's unique characteristics (e.g., age, severity of ASD-related symptoms.)4 For example, data from the U.S. Census Bureau³ reports that among grandparents with primary responsibility for at least one grandchild, 60 percent of those grandparents are aged 60 and older, with 19% living in poverty and 6.7% of those children not covered by health insurance.3 Among these U.S. grandfamilies, most, or 78%, receive some kind of public assistance, with 65% participating in school lunch programs and 35% receiving food stamps, 9% receiving SSI (Supplemental Security Income), 8% receiving Temporary Assistance for Needy Families (TANF) funding, and 6% receiving assistance for housing.3 Discrepancies among those grandfamilies also exist in terms of ethnic, racial, and geographic make-up. U.S. grandfamilies are more likely to be headed by Native and Innuit, and African American grandparents compared to White, non-Hispanic grandparents, and grandfamilies also tend to be overrepresented in U.S. southern states.³

Community-based and national resources for custodial grandparents, much less custodial grandparents of children with ASD, vary greatly,⁴ with their availability often moderated by national public policy and cultural stigma. For example, Sweden and many Scandinavian countries are noted for their wealth of ASD-related services,⁵ which offers grandfamilies of children with ASD access to publicly funded child habilitation centers that

deliver behavioral interventions, speech and occupational therapy, and both psychoeducation and social support for caregivers. Sweden also places an emphasis upon early screening and mainstream integration in education for children with ASD.6 Similarly, Finland, and Denmark provide services that include early intervention and inclusive education.⁵ Most EU countries also offer grandfamilies with a child with ASD an array of community-based services, including diagnostic assessments, inclusive education, and access to various therapies.⁵ Australia also provides ASD-related therapies through their National Disability Insurance Scheme.⁷ There is limited information regarding the availability community-based of resources grandfamilies with children with ASD in Mexico and Latin America, who tend to face limited availability of professional diagnostic and treatment services.

Custodial grandparents of a child with ASD in the U.S. are eligible for certain federal benefits, including a Medicaid waiver, also known as Home and Community Based Services waivers, which are administered by individual states.^{8,9} It is essential to note, however, that the ASD-related benefits and services provided by these waivers (e.g., providing health insurance for a child with ASD regardless of their parents' income; home-based services) vary significantly by state, and the rules and regulations to obtain those benefits can be complex.9 The Internal Revenue Service offers a fact sheet, Raising Grandchildren May Impact Your Federal Taxes, 10 which identifies tax benefits for qualifying grandparents raising children with ASD, including how to select the best tax filing status, possible tax emptions, available tax credits if they can claim their grandchild as a dependent, and qualifying ASD-related educational and medical expenses. Some legislation passed that provides support for grandfamilies of children with ASD includes the Supporting Grandparents Raising Grandchildren Act, 11,14 which established a federal task force and the Advisory Council to Support Grandparents Raising Grandchildren, designed to gather information and resources to help grandfamilies, with the goal of identifying best practices and gaps in resource needs.14

The U.S. Family First Prevention Services Act¹² allows states to use federal funds for preventive services, including Kinship Navigator Programs, which have been identified as a best practice model to support grandfamilies, including those with a child with ASD.14 Kinship navigators are specially trained professions who aim to connect custodial grandparents with state and local ASD- and legal-related resources, including legal advice in family and tax law.4 Additional areas of need identified for U.S. grandfamilies that apply to those with children with ASD include community-based services and support for respite care, childcare, and counseling for both grandparents and their grandchildren. Another identified need is affordable housing; the Grandfamily Housing Act¹³ and the Family First Prevention Services Act¹² both provide grants for affordable housing for grandfamilies, which is especially important because many grandparents live in housing that either does not allow, or is not suitable, for raising children, such as senior housing.14

Findings from this aforementioned federal task force¹⁴ revealed that grandparents raising a child with ASD are likely to be unaware of available national and state benefits, or that if they are aware of such communitybased resources, they do not know how to access them. Many grandfamilies have been reported to spend down their life savings to pay for health care and other services for their grandchildren, to find out later that they could have qualified for public or private assistance. Still other U.S. policies and programs, including TANF, may impose unnecessary or excessive burdens upon grandparents raising a child with ASD. For example, to qualify for TANF, grandfamilies must first be headed by a custodial grandparent. Because establishing custody of a grandchild is often costly in terms of both time and legal fees, many grandfamilies find themselves automatically excluded from this program's benefits. Second, those custodial grandparents must file an order of support against the non-custodial parent of the grandchild with ASD, which often means that the custodial grandparent must file a legal claim against their own adult child. Because the TANF benefit typically amounts to \$200 USD or less a month, many custodial grandparents simply avoid filing this legal order for support in an attempt to preserve family cohesion or to avoid incurring costly legal fees. These and other challenges with accessing a variety of community-based resources underscore the value of establishing effective Kinship Navigator Programs to support grandfamilies with a child with ASD.

To complicate matters further, the availability of community-based resources for grandparents raising children with ASD in the U.S. varies significantly¹⁵ by individual states' public policies9 and how they elect to structure and use available federal funding (e.g., block grants). In California, custodial grandparents are entitled to mandated insurance coverage for ABA therapy, specialized summer camps, and respite care, as well as financial aid for in-home domestic services, personal care, and protective supervision.¹⁶ California, Colorado, and Massachusetts are commonly recognized as states that offer a myriad of community-based resources for families of children with ASD,15 including relatively large numbers of schools that provide Applied Behavior Analysis, sensory integration training, diagnostic services, and additional availability of ASD-related services including speech, occupational, music, art, and equine therapy, respite care, and sensory friendly activities within the community. (An example of a sensory friendly activity could include having a local Autism Society of America chapter rent a movie theater for a private showing of a popular children's movie, with the theater lights turned on and the volume low to minimize sensory sensitivities for children with ASD.) In contrast, custodial grandparents of children with ASD in Mississippi typically face severe shortages of ASD-related professional providers and services, with long waiting lists for existing programs. Although Alaska is reported to have a fair number of community-based resources for grandfamilies with children with ASD, overall, those programs and trained professionals tend to be concentrated in one or two densely populated areas. Grandfamilies with a child with ASD in rural areas of Alaska, and rural areas in most U.S. states, typically face daunting travel times and distances

that may limit or preclude them from accessing those available resources.¹⁷

Another consistent finding in the literature is that early diagnosis is key for early intervention and more positive, long-term outcomes for children with ASD. Yet fewer than 17% of all U.S. counties offer community-based diagnostic services. 16,17 Based upon a variety of factors, including individual states' budgets, population density, and the impact of lobbying in local communities, grandparents raising a grandchild with suspected ASD in NJ would only need to travel two miles, on average, to obtain a formal diagnosis for their grandchild. In comparison, a grandparent raising a child with suspected ASD in Nevada would need to traverse more than 30 miles, on average, to have their child tested.¹⁷ These and other disparities in individual U.S. states' communitybased resources for ASD-related services are so significant that an estimated 20% of all primary caregivers of children with ASD have geographically relocated to gain improved access to community-based support services.16 However, with the majority of grandfamilies in the U.S. qualifying for public assistance,³ many grandparents who wish to move their families for better access to ASD-related services are less likely to have sufficient financial resources to even consider relocation, compared to their peers who do not qualify for public assistance.

Pervasive social stigma regarding ASD in various countries can also be expected to significantly impede provision of community-based services to grandparents raising children with ASD. In China for example,18 the term canfei, which signifies worthlessness, is commonly and unfortunately associated with ASD. And grandparents, who are typically revered in Chinese culture and expected to serve as de facto caregivers for their grandchildren, are also likely to be steeped in traditional cultural beliefs that if one family member has a disability or mental disorder such as ASD, the entire family's reputation may become blemished, with its members being viewed and treated dismissively by those in such a highly collective society. 19 Some grandparents in China may face deep seated concerns and apprehension about even having a grandchild who receives an official diagnosis of ASD, and experience both fear and shame.¹⁸

A recent systemic review¹⁹ revealed that such culturally based stigma may be predicated upon significant misunderstandings about ASD, and result in refusals of extended family members to engage in caregiving, as well as negative attitudes and discriminatory behavior against a child or grandchild with ASD. Many children with ASD are not invited to public or family gatherings. Both anecdotal and such documented reports describe how relatives of children with ASD in China,18 Saudi Arabia,²⁰ and other countries will literally hide them and their diagnosis within the parents' home, from not only their own neighbors and members of their own local community, but from members of their own extended family.18 This stigma only serves to virtually ensure that these children with ASD fail to receive appropriate treatment, education, or care. Also due, in part, to such intense, pervasive cultural stigma, the extent to which grandparents are raising grandchildren with ASD in China also remains unknown.

In response, China's Disabled Persons' Federation, a national organization that supports individuals with disabilities, initiated a nationwide program to educate the public about ASD.¹⁸ And in 2017, the State Council of China issued the Regulation on the Prevention and Rehabilitation of Disabled Persons,²¹ a national policy designed to promote inclusive education for children with ASD in mainstream public schools and preschools. This national policy was also designed to promote rehabilitation and treatment services for children with ASD, by improving treatment facilities, 18,19 providing enhanced medical insurance coverage for treatment, and fostering community support. However, no notable changes in China's public policy have emerged to examine or address the unique needs and communitybased resources available to grandfamilies of children with disabilities, including ASD.

Another aspect of globalization associated with attempts to mitigate cultural stigma against children and grandchildren with ASD that merits exploration is the extent to which the adoption of Western views of ASD among Chinese grandparents, compared to traditional cultural beliefs, may help custodial and non-custodial grandparents become more open to professional helpseeking.¹⁸ Although traditional Chinese values eschew professional help-seeking, promote avoidant coping strategies, and emphasize collective family orientations¹⁸, Western views and values tend to focus on the individual versus the family, and promote seeking professional, individualized treatment for both physical and mental health concerns, including ASD.²² A recent content analysis revealed that, with globalization, greater acceptance of Western views on ASD and professional help-seeking among Chinese parents has been associated a reduction in stigma, access to earlier intervention, and broader social networks, 19 including likely access to any available ASD-related community support. The extent to which these findings may generalize to grandparents of children with ASD, including grandfamilies with children with ASD, in that culture is unclear.

Similarly, traditional cultural beliefs in India, Ethiopia, and Kenya tend to associate ASD with divine or supernatural intervention, in which a child—and, by association, the entire family-- is being cursed or punished by the gods,²² or with assumptions that ASD is the direct result of inadequate or poor parenting.²³ (This view is similar to the pervasive myth ascribed to by many people in the West in the 1960's, when emotionally distant, socalled refrigerator mothers were believed to be responsible for causing autism in children.²¹) In some parts of India,^{23,24} China,¹⁸ and other countries, such negative cultural beliefs are so pervasive and stigmatizing that family members of children with ASD, including their grandparents, can expect social avoidance and disparaging remarks about that child, from not only their neighbors but from members of their own family. 14,18,19 Other traditional cultural beliefs in India, including one that boys speak later than girls,²⁵ can contribute to both

grandparents', and other relatives', tendencies to avoid help-seeking, including the establishment of a formal diagnosis of ASD.²³ In terms of ASD prevalence, children in both China, with a rate of 0.7%,26 and India, with its rate of $1.5\%^{27}$ are less likely to receive a formal of ASD than children in other countries,² including the U.S., with its rate of 3.2%.2 In contrast, in other parts of the world grandfamilies are common, and familial interdependence is considered a normal and positive aspect of life. In many parts of Africa, Asia, and Latin America, and in Aboriginal Australia, 14,19 for example, it is expected that grandparents and other extended relatives live in multigenerational households and share in child rearing.²⁸ However, the extent to which grandparents of children with ASD in those cultures serve as primary caregivers and advocates for those children also remains unclear.

It is also important to note that, while grandfamilies living in the U.S. can relocate freely between individual states if they have sufficient personal and financial resources to do so, grandfamilies in other nations may not enjoy the same freedom. Many grandfamilies, worldwide, who wish to immigrate to another country, whether it is for better access to ASD-related services or for any other reason, can find their options limited as well.²⁹ For example, New Zealand prohibits children (and people of any age) diagnosed with ASD, who would require significant support³⁰ (i.e., \$81,000 NZD over a five-year period) from applying for permanent residency. Grandfamilies with a child with ASD who wish to emigrate to Canada³¹ and Australia³² face similar restrictive policies, in which their grandchild's potential, ASD-related costs to a public health care system would be held against them, and prohibit their child's entry. Canada maintains a medical inadmissibility³¹ provision that can prohibit grandfamilies with a child with ASD from immigrating if their potential, ASD-related health care and social service costs are deemed too high. That cost threshold is \$27,162 CAD per year, or \$135,810 CAD over a fiveyear period. In comparison, Australia's Significant Cost Threshold is set at \$86,000 AUD over a 10-year period.³² Individuals who choose to support these nations' prohibitive policies argue that they are not necessarily ASD-specific, as they would prevent any child with a serious, costly physical or mental health condition from immigrating,³³ as those nations' available resources for requisite ASD-related education and care are finite and limited.

Conclusion

This editorial represents a call for routine, international health surveillance, based upon nationally representative samples,4 regarding the actual number, demographic and other characteristics, and the community-based needs of both custodial and non-custodial grandparents raising children with ASD. Assessing and acknowledging the numbers and unique characteristics and needs of grandfamilies from underrepresented groups within each nation (e.g., immigrants, LGBT, those with physical disabilities) is also essential. Although this call is for international surveillance,³⁴ it is consistent with findings from the U.S. Congressional Report of the Advisory Council to Support Grandparents Raising Grandchildren,¹⁴ which prioritizes increasing public awareness of both the community-based needs and the

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societal contributions of grandparents who raise grandchildren, including those who raise children with ASD. There is also an urgent need for more nations to adopt inclusive and supportive policies regarding ASD-related community resources for grandfamilies, and to investigate organized efforts to disrupt and dispel the cultural stigma surrounding ASD that many grandfamilies must face. Within the U.S., this editorial calls for more federal, versus individual, piecemeal state policies, to provide custodial grandparents and grandfamilies with adequate, uniform, evidence-based, ASD-related

education and care, irrespective of their state of residence. With consistent global increases in the prevalence of autism, these changes in public policy and service provision are urgently needed to provide support to some of the most underrepresented and underserved, yet essential caregivers of children with ASD, in the world.

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