

The Challenges of Daycare for Special Needs Children

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Abstract

The demand for day care services for children with special needs exceeds the current supply of such supports. This paper examines some of the causes of this disequilibrium and offers some policy recommendations to help reduce the magnitude of this problem.

Introduction

The COVID-19 pandemic has highlighted the critical role daycare facilities play in our everyday lives and our country's economy, as we know that "Childcare centers support a family-sustaining workforce" (United Way, 2021) (Hoopes et al., 2020). Over the last 40 years, the value of childcare centers, and their generally low availability, has been a topic of many households and in scholarly articles. Over the last 30 years, we have started to recognize that this issue was disproportionately troublesome to low-income families. It was only over the last 20 years that it has been acknowledged that the issue is also particularly troublesome for families with children with special needs.

Statistics from the National Center for Education Statistics (2021) shows a steady increase in the percentages of children in alternate forms of care (i.e. not a parent/guardian) through years 1991 – 2016, ages 3-5. The lowest utilization in 1991 was 53% of families using organized care. Since that time, this percentage has increased to 60%. The co-founder of Zippia.com, a career advice blogger with nearly 50 years of experience, used nine scholarly journal articles, many referenced in this paper, on daycare usage, showing that the figure of 60% of families roughly equates to roughly 6.5 million parents (Kolmar, 2022).

While there are over 54,000 childcare facilities in the United States (The Ground Level Inc., 2021), the average across the country is 37 facilities per 1000 children, using 2007 U.S. Census Bureau data. (U.S. Census Bureau, 2021), though Pennsylvania has a ratio of 50 "Child-Care Facilities" per 1000 children. However, 57% percent of all Pennsylvania residents live in a "childcare desert," or a location where the number of children greatly outweighs the childcare center availability (Pennsylvania Workforce Development Board Ad Hoc Committee 2020) (Novoa, 2020). Bucks County, Pa, has 283 "center-based childcare facilities" and zero facilities marked specifically for Children with Special Health Care Needs (childcarecenter.us)

Though typically families are expected to pay the cost of daycare through private pay means, families can apply for funding through Pennsylvania's CCIS (Child Care Information Services) for subsidized childcare. Funding is available to eligible low-income families, funded by the state and federal governments, and managed by the Early Learning Resource Center's (ELRC) county office. The average cost of childcare in Pennsylvania is almost \$300 per week, with a weekly range across all providers listed as \$148 to \$627, or roughly \$40 per day for infants and toddlers in Pennsylvania (Department Human Services, 2020).

The Economic Policy Institute reported that their study revealed that the cost of infant daycare in Pennsylvania is \$10,640 a year per child or \$887 per month and higher in the Philadelphia suburbs. The average price of infant daycare is just about \$60 less than the average cost of housing (Bivens et al., 2016). The childcare industry creates a combined revenue of more than \$21 billion, so it would seem, in that case, that it would be a lucrative plan to provide more daycare facilities. However, as noted by the Center for American Progress, despite the price tag, care centers are often "operating on slim budgets," constantly dealing with the costs of high turnover and losing teachers and aides to higher-paying positions. The rate of turnover is especially high considering the employees are who childhood special education teachers (Novoa, 2020) (Pennsylvania Workforce Development Board Ad Hoc Committee, 2020) (P.A. Care Gap PHI). The workforce crisis so frequently reported in the intellectual disability/autism field (Spreat, 2020) is strikingly evident throughout the day care industry.

Children with Disabilities

The need for childcare is no less evident among families of children with special needs (Booth-LaForce & Kelly, 2004). According to the Center for Disease Control and Prevention (CDC), one in five children in the U.S. is diagnosed with a Special Healthcare Need, equivalent to an estimated 20% of U.S. children (Novoa, 2020), or 1.5 million children (2012 NSECE household survey). 6.5 million children with disabilities are being served in the public school system, and this number continues to increase (NCES 2021-009). In 2014, the P.A. Autism Census update showed that since 2009, there was a "tremendous increase" in the number of individuals diagnosed with Autism, likely to increase the need for support personnel needed in homes and classrooms (Pennsylvania Workforce Development Board Ad Hoc Committee, 2020). It was reported by the American Academy of Pediatrics (AAP) in September of 2019, that 1 in 6 children, about 18% of US children were diagnosed with a Developmental Disability, ages 3-17. Durkin (2019) wrote that the findings on the increased numbers of those diagnosed with Developmental Disabilities, shows "the need for expanded services and training to meet the needs of children with developmental disabilities cannot be ignored).

The National Academy for State Health Policy estimated in 2018 that 14.6 million children ages Birth to 18 had chronic or complex health care needs (Hornsberger et al., 2018). Under the age of 6, an estimated 1.2 million have a condition that affects the way their parents cared for them. (Gebhart et al., 2020). It is this number that will most often be referred to in the plans to execute a special needs day, after and summer care program as this is the closest data set known to refer

to the number of families that might be caught up in this difficult life of no or insufficient childcare options due to their physical, medical or mental challenges.

Access to Traditional Care Organizations

Booth-LaForce and Kelly (2004) concluded that despite the "federal mandates about the inclusion of children with disabilities in childcare programs, many are not equipped to meet the needs of these children." In 2020, not much has changed; despite the regulations of the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) Act, and Section 504 of the Rehabilitation Act, daycare facilities, summer camps, and after school care organizations will still deny enrollment, and expel, children with special needs. A quick read of the Commonly Asked Questions page on ADA and childcare centers will reveal the caveat that allow centers to deny enrollment:

“If (the organization determines) the child needs one-to-one care to benefit from the child care program” the facility cannot deny enrollment if “a personal assistant will be provided at no cost to the child care center (usually provided by the parents or through a government program.” (U.S. Department of Justice, 2020).

The Center for American Progress (CAP) has made the call for federal enforcement of these mandates (Novoa, 2020), however, it doesn't appear that enforcement is the problem. The regulations have created a legitimate loophole that that enables a day care provider to reject an applicant. The issue would seem to be finding a way to close that loophole. The point is largely that this loophole allows too many special needs children to be denied enrollment (Novoa, 2020). The existence of this loophole allows day care providers to legally avoid the general expectations of the Americans with Disabilities Act.

Novoa (2020) suggested that Able-ism is the intentional or unintentional discrimination against people with disabilities" (Houtrow & Harris, 2020). It is discrimination favoring a perceived more "able"-bodied person (Boutin, 2011). Ableism is a critical factor in why political advocates must champion the call for more accessible childcare. Childcare 'slots' are already precious in so many states. Those slots are very unlikely to be offered to children who require more care, risk, time, supplies, and one-to-one attention (Novoa, 2020) (Houtrow & Debbi Harris, 2020). When parents call care facilities looking for enrollment of a special needs child, who are ultimately turned away, it is unlikely the parents believe the provider is purposefully or intentionally discriminatory when denying or dissuading enrollment (Novoa, 2020).

One must also note that a day care provider should not be punished for making operational decision based in simple economics; they cannot provide a service where the cost to provide the service outweighs the payment for those services. Nothing in the ADA requires a provider to willfully lose money.

When a parent is pressed for a reason as to why they tolerate this rejection of services, they will respond that safety is the reason. Inclusion may be 'right', though it still does not change the

very fact that most care facilities are genuinely ill-equipped or ill-staffed to provide the kind of attention the child should have. “Only 39% of all childcare centers in P.A. meets high-quality standards” (Pennsylvania Workforce Development Board Ad Hoc Committee, 2020). Safety will also be the response from the parent of a D/deaf and or nonverbal child (Novoa, 2020) (Booth-LaForce & Kelly, 2004). The pandemic only dramatically increased the likelihood that the families of these children would not be finding any daycare option any time soon (Houtrow, 2020).

Access to day care is the initial problem, but it is often accompanied by the challenge of retention. A common theme after several rejections or expulsions from day care programs, is that the parents will choose not to discuss any special needs, to whatever degree possible, during the enrollment period, opting instead to wait and see. Inevitably, parents get ‘the call’ once the daycare experience anything outside of the behavior expected by most typically developing children (i.e., transitioning, following 3-step instructions, or expectations that the child not be distracted by the various play centers). This phone call is often a game of semantics, ultimately informing the parent that the child can no longer attend if behavior X continues (Novoa, 2020) (Wolfram, 2020). Though noteworthy is the linguistics commonly experienced by parents, according to the facilities, “we don’t call it expulsion” (McCann, 2017). Preschool-age children in private care centers who become ‘disruptive’ are usually subject to a ‘soft expulsion’. However, often the disruption is a product of a child having special needs, such as Autism and Intellectual Disabilities (ASPE Office of Human Services Policy, 2017) (McCann, 2017) (Novoa, 2020) (Wolfram, 2020).

Zeng, et al (2020) used data from the National Survey of Children's Health of 2016 to determine that "Despite their negative effect, preschool suspension and expulsion are prevalent." The results from their study showed that young children with disabilities have been either suspended or expelled 5-times more frequently than those without disabilities and that "young children with attention deficit disorder or attention deficit hyperactivity disorder or reported behavioral or conduct problems were much more likely to experience exclusionary practices." In a Research Brief of 2017, The Department of Health and Human Services (Trivedi et al., 2017). reported that in just a 3-month time frame, 8.8% of *surveyed* childcare centers "denied services to children due to behavior". DHS also notes that for-profit centers generally expel children at a rate more than 3 times (3.2%) higher than non-profit centers.

What is Available for Special Needs Children

Since the *Olmstead v. L.C.* decision by the U.S. Supreme Court in 1999, a new system of integration, eligibility, and usage for medical and physical care assistance began, called "Home and Community-Based Services" (HCBS) (Foster, Agrawal, & Davis, 2019) (Williams & Musumeci, 2021). The intent was for the government and society to move away from institutionalized care to home or community-based care, as it was a less expensive and more humane way of managing care for those who need it.

While many do not argue that HBCS can be a healthy option for some, it is not a one-size-fits-all solution, and for many, this is not the best-suited form of care. However, families who wish to utilize the HBCS would be hard-pressed to find them. Finding services needed in the community is far from an easy task. A Google search on any keywords related to special needs daycare can be very misleading, full of misdirection, and phone calls to facilities do not produce transparent results. It is often at this time that after an exhaustive search for childcare, parents find themselves in need of special needs assistance for their children for the first time: overwhelmed and entrenched in a new world of paperwork, acronyms, and systems of care previously unknown to them. If they navigate successfully through the systems, they become eligible for services as recipients of Medicaid. Special Needs children are entitled to receive HCBS through “waivers and other state-specific Medicaid programs (Foster, Agrawal, & Davis, 2019, p. 988)” (Hornsberger, Holladay, Kim, & VanLandeghem, 2018).

For eligible families that find difficulty in finding appropriate daycare, after-care, or summer care, due to their child's complex or special medical needs, Medicaid will provide for an 'aide' under the Long-Term Supports and Services (LTSS). This policy governs Home Health Care for children in the form of a Private Duty Nurse (PDN), or a Home Health Aide (HHA), to assist the family with the medical and health needs of the child (ren). Theoretically, the provision of this aide should eliminate concerns over the ADA loophole referenced above, however, the answer is not that simple. First, one must successfully negotiate the waiting list for services. In 2019, 14 states had pediatric waiting lists for HCBS waivers, often resulting in families simply not receiving the services (Foster, Agrawal, & Davis, 2019). Second, an agency must locate the aide in the midst of a long term workforce crisis in the intellectual disability field, where vacancy rates approach 20% (Spreat, 2020). Third, if one is successful in obtaining the services of an aide, there are still other significant barriers that contribute to the ‘patchwork’ nature of utilizing LTSS services.

Barriers to the Utilization of LTSS- a summary

Barriers for the family only begin with the Medicaid 3–6-month eligibility process, which is nothing short of a feat of emotional strength and determination.

The next hurdle is in the availability of the aides. Even prior to the pandemic, families could easily wait weeks. Post-pandemic, families waited months. As of Spring 2022, families in the suburbs, can easily wait over a year, as the aide is not reimbursed for travel time. 50 million direct care workers are already in demand with the number steadily rising. There are simply not enough direct care workers accepting cases that offer a choppy schedule, a low wage and an unpredictable paycheck with little no advancement possibilities.

If an aide does pick up that family’s case, one of two scenarios occur: the parents then must decide if the aide will stay at home alone with the child while the parent(s) work, or if they wish to, or can afford to, will they have the aide accompany the child to a private-pay daycare. Many families would like to see their children have the chance to develop age-appropriate social skills that comes naturally with peer modeling and play, as well as the chance for themselves to build

inter-community relationships with other parents. If they are financially able to enroll in a tuition-based program, and if they're request for enrollment is accepted, as they are now a 'two-some', their tuition is chronically at risk of being lost, and the child expelled, should the aide be unable to continue the case. This is because the aides tend to be primarily women, and many parents themselves, they are often called upon mid-day to leave work and tend to their own children.

Another inherent issue is transportation. If the aide is to accompany the child to a tuition-based program (as a paid Home Health Aide) may not drive the child client anywhere. Therefore, any opportunities for inclusion into care centers would require the care facility to allow for drop off and pick up in hours that a parent can manage while working, therefore the center would need to be open for the full span of the workday plus travel time, or be close enough for the aide and child to walk despite the cold and heat. This also would most likely require the aide to have their own transportation, eliminating aides who use public transportation.

Consequently, if the aide does then work in the family home, the child is now isolated, without socialization or play with peers. All the while having (due to turnover) multiple strangers have access to keys, and everything inside your home, and no other oversight when alone with your child. All this and still the family is beholden to one person's ability to arrive at work.

Also, though the same tuition risks apply, parents might desire a socially active opportunity in Summer Camp, though they tend to have hours shorter than the average workday, are much less likely to be within walking distance, and can be solely designed for outside play, without indoor options for heat relief, unsuitable for many special needs children.

These are just some of the many reasons that there are nearly 17 million unpaid caregivers providing care to special needs children under the age of 18, spending nearly 30 hours per week providing care. It is not uncommon for families to feel they have no choice but to accept care from people who are: untrained and inexperienced, perhaps entirely too young for this burden, and sometimes at best, from paid caregivers who are entirely deficient in the position to the point of dangerous.

The inadequacy of the LTSS model has some families "resorting to litigation" (Foster, Agrawal, & Davis, 2019, p. 989). Perhaps the most impactful article to date Foster, et al., begin by stating this fact: "Home Health care for children and adolescents is an understaffed health care model that does not meet the current needs of patients and families" (Foster, Agrawal, & Davis, 2019).

Social Determinants of Health

Without the opportunity for equitable, safe, stable, appropriate, publicly accessible organized care options for children with special health care needs, these families will be negatively impacted and negatively impact, respectively, each category of the Social Determinants of Health (SDOH) as defined by the Robert Wood Johnson Foundation, where 80% of the social and socioeconomic factors are most likely to absorb the impact: Length of Life, Quality of Life,

Health Behaviors, Clinical Care, Social and Economic Factors, Physical Environment (Nash, Skoufalos, Fabius, & Oglesby, 2021) (Hinton & Stolyar, 2021).

The Health of the Family

The Center for American Progress, in January 2020, issued a 22-page meta analyses called “The Child Care Crisis Disproportionately Affects Children with Disabilities”. These analyses used data from three annual survey’s by the U.S. Census Bureau's National Survey of Children's Health (NSCH), from 2016 to 2018. The author Christina Novoa, the Senior Policy Analyst, specifically noted that a columns marked ‘multiple arrangements’ left more questions than answers, and decided to dig deeper into the data. Novoa interviewed these families to qualitative data (in the form of interviews), to ask what she called ‘one key question’: “During the past 12 months, did you or anyone else in the family have to quit a job, not take a job, or greatly change your job because of problems with childcare for this child?” The result was that “families with disabled children were three times more likely to experience job disruption” due to childcare with a disabled child (pp. 3, 18).

In 2011, Kuo, Cohen, Agrawal, Berry, & Casey reported that nearly 57% of the families with special needs children had financial problems, over 54% required a family member to stop working, nearly 50% had ‘unmet medical needs’, and over 33% "reported difficulty accessing non-medical services" (Kuo, Cohen, Agrawal, Berry, & Casey, 2014). Foster, Agrawal, & Davis (2019) later reported that “family caregivers are frequently shouldering enormous burdens that lead them away from their own gainful employment” creating “social, emotional, and financial hardships” due to "insufficient and inadequately trained workforce" in a "patchwork of policies and programs that does not currently meet “the needs of these families” (Foster, Agrawal, & Davis, 2019).

Parents of special needs children are “twice as likely to state they are in poor health”, (National Alliance for Caregiving in Collaboration with AARP, 2009, p. 6) because of “the heavy caregiving burden" that negatively affect[s] their health” (Berry, et al., 2016, p. 2) (Kuo, Cohen, Agrawal, Berry, & Casey, 2014) (Houtrow & Debbi Harris, 2020) (Novoa, 2020).

Depending on the level of medical complexity, a family's finances and structure, these facts speak volumes: the crumbling infrastructure of the fragmented LTSS delivery system is causing tremendous financial, emotional and physical suffering and has an incredibly negative ripple effect throughout the health, and fiscal health, of our Population (Kuo, Cohen, Agrawal, Berry, & Casey, 2014) (Foster, Agrawal, & Davis, 2019) (Houtrow & Harris, 2020) (Whiting & Monaco, 2017) (Williams & Musumeci, 2021) (Pennsylvania Workforce Development Board Ad Hoc Committee, 2020) (American Autism Association, 2020) (National Alliance for Caregiving in collaboration with AARP, 2009) (Novoa, 2020, p. 12) (Berry et al., 2016) (Kuo, Cohen, Agrawal, Berry, & Casey, 2014) (Nash, Skoufalos, Fabius, & Oglesby, 2021, p. XVIII).

Many parents, especially for low-income and single parents, who will be driven from the workforce due to their children's special needs, further exacerbating economic inequalities between families of disabled and nondisabled individuals.

The Health of The Population

Without or without a pandemic, nothing will send a family down the Chutes & Ladders of life faster than a special needs child with medical complexities. There is not another report or study that so perfectly and succinctly describes this phenomenon than the one done by the Center for American Progress in their report: "The Care Crisis Disproportionality Affects Children with Disabilities". This report highlights the "disproportionately high rates of poverty among people with disabilities" (Novoa, 2020, p. 11), that forces so many to rely on public welfare programs in addition to Medicaid; such as Women Infant and Children (WIC), Children's Health Insurance Protection (CHIP), Supplemental Nutrition Assistance Program (SNAP), Low Income Energy Assistance Program (LIHEAP), and more.

When children are not in parental care because the parent is employed and without organized care center options, our most vulnerable children are left in the care of over-used friends and neighbors, under-age siblings, and exhausted relatives and grandparents (Wolfram, 2020). More than 4 in 10 felt they had no choice (National Alliance for Caregiving in collaboration with AARP, 2009) (Foster, Agrawal, & Davis, 2019) (Berry et al., 2016) (Novoa, 2020).

Summarizing the Need

This service gap often puts families of special needs children in formidable positions that can dramatically affect their livelihood, and mental and physical health. Making matters worse, is that the burden is then often over-shared with unpaid caregivers who may be providing desperately needed, albeit often inappropriate, support to the detriment of the health and safety of both parties. Families often turn to public assistance programs to offset the changes to their income, costing the country billions per year. For a very, very long time, the need for childcare has been increasing, and the availability of paid caregivers has been consistently decreasing.

Despite the federal mandates, when organized care centers deny enrollment or expel children with special needs, the child may qualify for Medicaid Long Term Supports and Services to provide a paid Home Health Aide for the family.

There is no shortage of evidence that parents with special needs children face more barriers to working and maintaining a stable income than families with nondisabled children due to a lack of childcare opportunities that diminishes their work opportunities. "That kind of situation is all too common" says the Corporate Officer of Behavior and Development Services at the Center for Special People in the Northeast (SPIN) in Philadelphia (Wolfram, 2020) (Novoa, 2020).

The CEO of Independence Health Group says, "Access to behavioral health care is incredibly challenging in the current health care ecosystem" (George, 2021).

Without the opportunity to enroll in equitable, safe, stable, appropriate, publicly accessible organized care, families that have CSPHCS will suffer adverse impacts throughout all areas that are the Social Determinants of Health: socioeconomic/financial, education, neighborhood, physical environment, employment, social support networks, and access to healthcare), including, loss of employment, financial hardships beyond the average family, and are likely to suffer physically and mentally (Hinton & Stolyar, 2021) (Nash, Skoufalos, Fabius, & Oglesby, 2021) (Hinton & Stolyar, 2021).

The possible number of families in this position adds incredible negative impacts to The Social Determinants of Health to the population. It is also likely that many of these families with special needs children are also in the ALICE threshold, which, without public childcare, are forced to rely on one or many forms of public assistance, stressing taxpayer dollars unnecessarily.

Conclusion of Research

1. The demand for day care services for children with special needs exceeds the supply of such programs. Additional funding is needed to establish an equilibrium between supply and demand.
2. The inability of families to locate and obtain day care services for their children with special needs is directly responsible for economic, emotional, and physical health challenges.
3. The ongoing workforce crisis in the broadly defined intellectual disability/autism area continues to impact the provision of day care services for children with special needs.
4. The provision of day care for children with special needs is beset by numerous bureaucratic challenges, including the provision of transportation and the portability of Home Health Aides.
5. In 2015, “the agency for Healthcare Research and Quality developed six National Quality Strateg[ies]” to address “health equality and patient safety, noting, “Care Affordability” as number six on the list: “Making quality care more affordable for individuals and families employers and governments by developing and spreading new health care delivery models” (Nash, Skoufalos, Fabius, & Oglesby, 2021). The same absolutely must be applied to the equality and safety of special needs children in care.

The damage that this fractured, perhaps now broken, delivery system has caused, is immeasurable. We must no longer allow special needs children to be denied access to organized care facilities. We must build appropriate care facilities for special needs children. We can no longer afford for those families to be at such a high risk for total dependency on the finances of the local, state, and federal government while simultaneously, and negatively, adding to the decline in statewide, if not countrywide, public health. CAP has called for congressional action to address the fragile balance between work and family when lack of organized care for children with disabilities “disproportionately affects families of children with disabilities” (Novoa, 2020).

Policy Recommendations

1. The “Child Care for Working Families Act of 2019” to “ensure access to high-quality, affordable childcare for working families” and to “improve wages for child care workers” needs to be reintroduced and passed. Done correctly, this bill would increase special needs eligibility and funding, such that a) middle class parents are able to place a special needs child in daycare, and b) the disincentive to accept a special needs child into day care is removed. The ADA loophole must be closed, and the closure cannot come at the expense of the day care provider or of the parent.
2. Funding for day care providers must be sufficient to enable them to hire a sufficient number of qualified staff to meet the legitimate needs for day care staff.
3. Day care services need to be broadened, such that Home Health Aides and transportation are included in the package.
4. Funding for special needs day care must be adjusted for acuity levels of the child, such that children with greater support needs draw a greater compensation for the provider. Note that we are experiencing a disequilibrium between the demand for special needs day care and the supply of special needs daycare. Cost is generally the factor that can create an equilibrium between the two concepts. Failure to consider basic rules of supply and demand will only result in a continuing crisis.
5. The Center for American Progress called for a “new funding stream to provide services in childcare settings and allowing providers funds to construct or renovate to improve accessibility” (Novoa, 2020) CAP also called for Congress to “significantly increase funding for IDEA early childhood programs by triple the 2019 funding to 2.95 billion by 2024”.

References

- Berry, J. G., Hall, M., Neff, J., Goodman, D., Cohen, E., Agrawal, R., Kuo, D., & Feudtner, C. (2014). Children with medical complexity and Medicaid: Spending and cost savings. *Health Affairs*, 33(12), 2199–2206. <https://doi.org/10.1377/hlthaff.2014.0828>
- Bivens, J., Garcia, E., Gould, E., Weiss, E., & Wilson, V. (2016). Economic Policy Institute. *It's time for an ambitious national investment in America's children* (p. 38). <https://www.epi.org/publication/its-time-for-an-ambitious-national-investment-in-americas-children>
- Block, P. (2018). *Community, The Structure of Belonging* (2nd ed.). Berrett-Koehler Pub, Inc.
- Booth-LaForce, C., & Kelly, J. F. (2004). Childcare patterns and issues for families of preschool children with disabilities. *Infants & Young Children*, 17 (1), 5–16. <https://doi.org/10.1097/00001163-200401000-00004>
- Bowleg, L. (2020). We're not all in this together: On covid-19, intersectionality, and structural inequality. *American Journal of Public Health*, 110 (7), 917–917. <https://doi.org/10.2105/ajph.2020.305766>
- Chandler, L. W. & D. (2021, May 3). *Building relationships with payers at the State Level*. HomeCare Magazine. <https://www.homecaremag.com/cmsmedicare-medicare-reimbursement-billingreimbursement/may-2021/building-relationships-payers>
- Crutchfield, L. R., & McLeod Grant, H. (2008). Introduction. In *Forces for good: The six practices of high-impact nonprofits* (First, pp. 1–313). essay, Jossey-Bass.
- Cusick, J., Seeberger, C., Oduyeru, L., Gordon, P., Shepherd, M., Director, J. P. D., Parshall, J., Malik, R., Hamm, K., & Novoa, C. (2021, November 7). *How childcare disruptions hurt parents of color most*. Center for American Progress. <https://www.americanprogress.org/article/child-care-disruptions-hurt-parents-color>
- Davis, M., & Dawson, S. L. (2003). (rep.). *Pennsylvania's Care Gap: Finding Solutions to the Direct-Care Workforce Crisis*. Paraprofessional Healthcare Institute. <https://www.paproviders.org/archives/secure/Toolkits/Workforce/3.2.pdf>
- Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE, Office of Human Service Policy), Trivedi, P., Chadwick, L., & Burgess, K., Research Brief: *Preliminary findings from the National Survey of Early Care and Education*, pgs. 1–16 (2017). <https://www.hhs.gov/ashpe/docs/data-research/2017/01/2017-01-16-nsece-research-brief>

- Department of Health and Human Services; Pennsylvania. Office of Child Development and Early Learning. (2020). Childcare and early education research connections. *Pennsylvania's 2019 childcare market rate survey report*. <https://www.researchconnections.org/childcare/resources/38851>
- Diamant, M. (2021, May 17). *Biden Administration Gives States Flexibility to Expand Disability Services*. Disability Scoop. <https://www.disabilityscoop.com/2021/05/17/biden-administration-gives-states-flexibility-to-expand-disability-services/29342/>
- Durkin, M. S. (2019). Increasing prevalence of developmental disabilities among children in the US: A sign of progress? *Pediatrics*, 144 (4). <https://doi.org/10.1542/peds.2019-2005>
- Foster, C. C., Agrawal, R. K., & Davis, M. M. (2019). Home Health Care for Children with Medical Complexity: Workforce Gaps, Policy, and Future Directions. *Health Affairs*, 38(6), 987–993. <https://doi.org/10.1377/hlthaff.2018.05531>
- Gebhart, T., Warner-Richter, M., Boddicker-Young, P., Hooper, A., Halle, T., & Hallam, R. (2020). (CCEEPRA). *Who Provides Early Care and Education for Young Children with Special Needs?* (pp. 1–8). Who provides early care and education for young children with special needs? Findings from the 2012 NSECE (hhs.gov)
- The Ground Level Inc. (2021, April 21). *Why do daycare centers fail?* The Ground Level Inc. <https://thegroundlevelinc.com/blogs/news/why-do-daycare-centers-fail>
- Hinton, E., & Stolyar, L. (2021, August 4). *Medicaid authorities and options to address social determinants of Health (SDOH)*. KFF. <https://www.kff.org/medicaid/issue-brief/medicaid-authorities-and-options-to-address-social-determinants-of-health-sdoh>
- Hinton, E., Stolyar, L., & Rudowitz, R. (2020, November 2). *10 Things to Know About Medicaid Managed Care*. <https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-managed-care/>
- Home and Community Based Providers, Inc. (2019, December 12). *The Pennsylvania Waiting List Campaign – What You Need to Know*. HCBS Home Community Based Services. <https://hcbsprovider.com/the-pennsylvania-waiting-list-campaign-what-you-need-to-know>
- Hoopes, S., Abrahamson, A., Anglin, A., Connelly, C., Holdsworth, M., & Treglia, D. (2020). (rep.). *2020 ALICE Report for Pennsylvania*. United Way. <https://www.uwp.org/wp-content/uploads/2020-ALICE-Report-for-Pennsylvania.pdf>
- Hornsberger, K., Holladay, S., Kim, E., & VanLandeghem, K. National Academy for State Health Policy (NASHP). *How States Use Medicaid Managed Care to Deliver Long-Term Services and Supports to Children with Special Health Care Needs-A 50 State Review of*

MCO Contracts. <https://www.nashp.org/wp-content/uploads/2018/11/MLTSS-for-CYSHCN-Master-Slide-Deck-FINAL.pdf>

Houtrow, A., Harris, D., Molinero, A., Levin-Decanini, T., & Robichaud, C. (2020). Children with disabilities in the United States and the COVID-19 pandemic. *Journal of Pediatric Rehabilitation Medicine*, 13(3), 415–424. <https://doi.org/10.3233/prm-200769>

Hughes, S. A. (2019, July 20). *As Pa. Faces Home-Care Worker 'Crisis,' lawmakers set the stage for a small wage increase*. Star. <https://www.penncapital-star.com/health-care/as-pa-faces-home-care-worker-crisis-lawmakers-set-the-stage-for-a-small-wage-increase>

Irwin, V., Zhang, J., Wang, X., Hein, S., Wang, S., Roberts, K., York, A., Barmer, C., Bullock Mann, A., Dilig, F., & Parker, S. (2021). U.S. Department of Education: National Center for Education Statistics. *Report on the Condition of Education 2021 (NCES 2021-144)*, 1–34. <https://doi.org/https://nces.ed.gov/pubs2021/2021144.pdf>

Jenco, M. (Ed.) Study: 1 in 6 Children has a Developmental Disability. *American Academy of Pediatrics*. 2019. [Study: 1 in 6 children has developmental disability | AAP News | American Academy of Pediatrics](https://www.aap.org/news/2019/07/11/study-1-in-6-children-has-developmental-disability)

Kuo, D. Z., Cohen, E., Agrawal, R., & Berry, J. G. (2011). A National Profile of Caregiver Challenges of More-Complex Children with Special Health Care Needs. *Archives of Pediatrics & Adolescent Medicine*, 165(11), 1020. <https://doi.org/10.1001/archpediatrics.2011.172>

Laughlin, L. (2013, April). *Who's minding the kids? childcare arrangements: Spring 2011*. Census.gov. <https://www.census.gov/library/publications/2013/demo/p70-135.html>. (pp. 70-135).

McCann, C. (2017, September 18). *Expulsion and suspension in early childhood settings: .* https://www.ncsl.org/documents/cyf/ExpulsionSuspension_31153.pdf

Nash, D. B., Skoufalos, A., Fabius, R. J., & Oglesby, W. H. (2019). Preface. In *Population health: Creating a Culture of Wellness* (3rd ed., pp. 1–335). essay, Jones & Bartlett Learning.

National Alliance for Caregiving in collaboration with AARP. (2009, November). *Caregivers of Children: A Focused Look at Those Caring for A Child with Special Needs Under the Age of 18*. www.caregiving.org . https://www.caregiving.org/wp-content/uploads/2020/05/Report_Caregivers_of_Children_11-12-09.pdf

National Alliance for Caregiving and Global Genes Have Launched a New Study of Caregivers for Persons with Rare Disease. *Rare Disease Families Front and Center in Upcoming*

Caregiving Study. (2017, August 31). <https://www.caregiving.org/rare-disease-families-front-and-center-in-upcoming-caregiving-study>

National Center for Education Statistics (NCES) Home Page, a part of the U.S. Department of Education. *The NCES Fast Facts Tool provides quick answers to many education questions.* <https://nces.ed.gov/fastfacts/display.asp?id=4>

National Center for Education Statistics, The Condition of Education, Students with Disabilities May 2021. <https://nces.ed.gov/programs/coe/indicator/cgg>

National Center for Education Statistics (NCES) Home Page, a part of the U.S. Department of Education. Digest of Education Statistics, 2019. *Childcare arrangements of 3- to 5-year-old children who are not yet in kindergarten.* https://nces.ed.gov/programs/digest/d19/tables/dt19_202.40.asp

National Center for Health Statistics. Federal Interagency Forum on Child and Family Statistics (2021, September). *America's children: Key national indicators of well-being, 2021.* [childstats.gov. https://www.childstats.gov/pdf/ac2021/ac_21.pdf](https://www.childstats.gov/pdf/ac2021/ac_21.pdf)

Novoa, C. (2020). *The Child Care Crisis Disproportionately Affects Children with Disabilities* (pp. 1–22). American Progress.org.

Oshry, B. (1996). *Seeing Systems Unlocking the Mysteries of Organizational Life.* Berrett-Kohler Publishers.

Patrick, S., & Gabriel, P. (2011). *Collaborative Leadership in Action.* HRD Press. Inc. Pennsylvania Workforce Development Board (PA WDB) . (2020). (rep.). *Professional Care Worker Shortage Crisis Statement.* <https://www.dli.pa.gov/Businesses/Workforce-Development/wdb/Pages/default.aspx>. Quarterly Meeting Briefing Book, Pg 25.

Perrin, J. M., Romm, D., Bloom, S. R., & Homer, C. J. (2007). A family-centered, community-based system of services for children and youth with special health care needs. *Archives of Pediatrics & Adolescent Medicine, 161*(10), 933. <https://doi.org/10.1001/archpedi.161.10.933>. Et al.

Sauro, S. (2019, June 20). *More than a third of Pennsylvanians don't make enough to pay for food, housing: Report.* pennlive. <https://www.pennlive.com/news/2019/06/household-incomes-of-37-percent-of-pennsylvanians-cannot-cover-cost-of-basic-necessities-report.html>

Seymour, K. (2016, April 12). *Daycare almost as much as housing in Pa., new study finds.* Newtown, PA Patch. <https://patch.com/pennsylvania/newtown-pa/daycare-almost-much-housing-pa-new-study-finds>

- Spreat, S. (2020). *Crises in Intellectual Disability*. London: Cambridge Scholars Publishing.
- Torres, N., & Hanson-Turton, T. (2018). *Practical Tools for Not-for-Profit Leaders*. Social Innovations Publishing Co.
- United States Census Bureau, Grandparents Still Work to Support Grandchildren (2018). <https://www.census.gov/programs-surveys/acs>
- United States Department of Health and Human Services, Health Resources and Services Administration The National Survey of Children with Special Health Care Needs Chartbook 2009–2010 (2011). <https://mchb.hrsa.gov/sites/default/files/mchb/data-research/nscsh-chartbook-06-2013.pdf>
- United States Department of Justice Civil Rights Division Disability Rights Section. (2020, February 24). *Commonly asked questions about childcare centers and the Americans with disabilities act*. Commonly Asked Questions About Child Care and the ADA. <https://www.ada.gov/childqanda.htm>
- United Way of Pennsylvania. (2019). (rep.). *ALICE in Pennsylvania: A Financial Hardship Study*. <https://www.uwp.org/alice/about-alice>
- United Way Pennsylvania : COVID-19 Pandemic Report : Child Care is Essential for Working Families and Businesses. (2021).
- United Way of Pennsylvania. *United Way Survey seeks to understand pandemic impacts on PA families*. (2021, March 15). <https://www.uwp.org/2021/03/united-way-survey-seeks-to-understand-pandemic-impacts-on-pa-families>
- Williams, E., & Musumeci, M. B. (2021, October 4). *Children with special health care needs: Coverage, affordability, and HCBS Access*. KFF. <https://www.kff.org/medicaid/issue-brief/children-with-special-health-care-needs-coverage-affordability-and-hcbs-access>
- Wolfram, J. (2020, February 21). *Autism and child care: How a lack of quality programs hurts families*. WITF. <https://www.witf.org/2020/02/21/autism-and-child-care-how-a-lack-of-quality-programs-hurts-families>
- Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., Blumberg, S. J., Kogan, M. D., & Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009–2017. *Pediatrics*, *144*(4), 1–11. <https://doi.org/10.1542/peds.2019-0811>
- Zeng, S., Pereira, B., Larson, A., Corr, C. P., O’Grady, C., & Stone-MacDonald, A. (2020). Preschool suspension and expulsion for young children with disabilities. *Exceptional Children*, *87*(2), 199–216. <https://doi.org/10.1177/0014402920949832>