

Chapter 10

Understanding Legislation, Health Insurance, and Disparities in Service Provision in Autism Early Intervention



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Individuals with Disabilities Education Act

In the United States, the provision of educational services to children with disabilities from birth to 21 years of age is mandated by the Individuals with Disabilities Education Act (IDEA, 2004). Under this law, children with disabilities are eligible to receive a free (i.e., publicly funded) and appropriate public education (FAPE), which would result in meaningful benefit to the child. IDEA also specifies a preference that children receive these services in a least restrictive environment (LRE), which for school age children means placement in classrooms alongside their typically developing peers as opposed to segregated settings. Finally, IDEA provides procedural safeguards that outline referral, assessment, education planning, service provision, and progress monitoring processes. Below, we provide an overview of this federal law in relation to both early intervention services prior to school entry (Part C and Extended Part C), and school-based services (Part B).

Early Intervention Services Under IDEA Part C

Under Part C of IDEA, eligible children under the age of 3 may receive early intervention services, which are preferentially delivered in the home setting with the participation of caregivers. The services provided vary by state, and may include combinations of parent- and practitioner-provided interventions, with different states favoring different modes of delivery and types of services (Stahmer &

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Mandell, 2007). There are two categories of eligibility under which children may qualify for early intervention services. The first category applied to children who exhibit developmental delays, and the second applied to children with established conditions putting them at substantial risk of developmental delay. Given that a reliable ASD diagnosis is not usually made until after age 2, many children with ASD become eligible under the developmental delay category prior to an ASD diagnosis. Eligibility under this category involves a determination as to whether or not the child is experiencing delays (with thresholds set by individual states) in at least one of five categories: cognitive, social–emotional, speech and language, adaptive, and physical development (Early Childhood Technical Assistance Center, n.d.). Although most states use federal guidelines at least in part to establish eligibility criteria, there is some variation from state to state that seems to translate to variation in the proportion of young children with ASD who receive early intervention (Barton et al., 2016).

Once children are found eligible for early intervention services, service providers work with families to develop an individualized family service plan (IFSP) that can include services provided to both the child and the caregivers. These often include, but are not limited to, applied behavior analysis, speech therapy, occupational therapy, or other psychosocial treatments. IDEA Part C stipulates that these plans should be tailored to meet the needs of individual children, and should consider parents' input in regards to service selection. However, early intervention providers are not required to implement services desired by the family if they are able to provide other services that would convey the same benefit. There is also a lack of clarity in federal law regarding service intensity (i.e., the number of treatment hours) that must be provided through early intervention, which reflects a lack of research evidence in this regard (Dicker, 2013). The American Academy of Pediatrics recommends at least 25 h/week of intervention services with low child to teacher ratios, which should be delivered year round (Myers & Johnson, 2007). Even given these recommendations, there is no explicit provision that IFSPs must provide this level of intensity for every child.

Transition to School Under IDEA Part B

Some states offer transitional services from age 3 to kindergarten enrollment, known as “Extended Part C.” These services are meant to support the transition between early intervention services and entry into the school system. If children are not receiving Extended Part C services or have aged out of these services, they then transition to IDEA Part B services. IDEA Part B is the section of federal law that mandates special education services for children and youth ages 3–21. This law lists 13 specific disability categories under which children may be eligible to receive educational interventions, one of which is autism. Children either transition from an IFSP into an individualized education program (IEP) developed by a team of school professionals, administrators, and the child's caregivers, or are referred for an

evaluation once they reach school age to determine eligibility. Because services are generally more comprehensive and family centered under Part C as compared to Part B, there is sometimes conflict during the transition periods as families work with schools to determine which services will continue through the child's school-based program, and which will be revised or discontinued (Dicker, 2013). Similar to Part C services, school-based services can include various types of programming, which can be delivered by classroom teachers or other licensed (and in some cases unlicensed) professionals. Because of the LRE provision of IDEA, many more children with ASD are educated alongside their typically developing peers than have been in the past (Morningstar, Kurth, & Johnson, 2017).

Just as is the case with IDEA Part C services, court cases have determined that Part B educational services need only provide meaningful benefit and are not required to be the best services possible (Dicker, 2013). Because federal dollars only account for a small portion of special education funding and the remaining costs are left to states, there is wide state-by-state variation in educational supports provided to children and youth with ASD. We discuss this issue in more detail in the final sections of this chapter.

Insurance Coverage for Diagnostic and Early Intervention Services

Given the support needs of children with ASD, which can include services directly related to the diagnosis as well as any and accompanying health conditions, health-care costs are substantially higher for these children as compared to children who are typically developing (Buescher, Cidav, Knapp, & Mandell, 2014). Services provided to children with ASD in the United States can be covered by a combination of school agencies, insurance providers, and Medicaid, a federal and state program that helps with medical costs for some people with limited income and resources (Dicker, 2013). As of 2017, 46 U.S. states and the District of Columbia have passed legislation mandating insurance funding for ASD diagnostic services and interventions (National Conference of State Legislatures, 2018). Prior to these mandates, insurers often denied coverage for ASD-related services, citing a lack of clear evidence of effectiveness for most interventions (Mandell et al., 2016). These new mandates appear to have increased service utilization and the proportion of spending by insurers, and this is especially true for families who spend more on services (Candon et al., 2019).

However, even given that legislative mandates are widespread across states, there still remains ample variability in the nature of services covered, and the extent to which services are covered by private insurers. Due to federal restrictions, insurance coverage is limited to families with fully insured plans, which means those who are self-insured may not be covered (Candon et al., 2019). There is also variability across states in expenditure caps, which can range as low as \$12,000 and as high as

\$50,000 (Mandell et al., 2016). Because of limitations in study designs, it is not clear if insurance mandates have improved service access across all SES strata, but this might not be the case given that low SES families are least likely to be insured. Due to a variety of factors, including barriers posed by insurers, the number of children with ASD who receive insurer-covered services is well below what would be expected given the prevalence of ASD (Mandell et al., 2016). Still, improvements in access to care under state insurance mandates are expected to continue into the future (Mandell et al., 2016).

At present, there is a lack of clarity and continued debate in regards to whether specific services should be covered by insurance providers, by local school systems, or be paid out of pocket by families (Bilaver, Cushing, & Cutler, 2016; Holland, 2010). Many states explicitly specify insurance coverage of applied behavioral analysis but leave requirements for other intervention and service types more vague (NCSL, 2018). This can lead families toward services that are more likely to be covered, regardless of their appropriateness or effectiveness.

Regional Variation in Service Access and Utilization

Another factor contributing to variability in service provision for children with ASD in the United States is geographic location. Programming enacted through Part C of IDEA is supported by way of federal formula grants, which are proportionally determined based upon the number of children under 3 years of age reported to reside in a given state (Noyes-Grosser et al., 2018). Federal funding contingent on population data is one reason for geographic differences in access to services, which is often stratified on rural and urban/suburban lines. For example, attaining an early diagnosis is often more difficult in rural as compared to urban or suburban areas (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017; Kalkbrenner, Daniels, Emch, Morrissey, Poole, & Chen, 2011; Singh, Moody, Rigles, & Smith, 2018). Additionally, parents living in rural communities report reduced service availability than did those residing in urban environments (Centers for Disease Control, 2011). Delays in receiving diagnoses and support services often occur in rural areas due to limited overall awareness, inadequate screening procedures, and increased demands on families to travel greater distances to locations more equipped with available supports (Antezana et al., 2017).

Due to limitations in the health care systems within rural communities, families often rely more heavily on other sources, like the school community, for service support. One corollary of this is that, according to the SPSD, rural parents demonstrate lower rates of communicating concerns with healthcare providers as compared to nonrural parents. Within rural communities, healthcare providers are also more likely to encourage parents to consult school personnel than do healthcare providers within urban communities (Antezana et al., 2017; Centers for Disease Control, 2011).

There may also be differences between rural and urban/suburban communities in terms of the supports they most value. For example, within more metropolitan regions, behavior supports are held in higher regard than in rural communities while rural communities place a higher value on speech and language therapies than do families in nonrural areas (Murphy & Ruble, 2012). This difference can be explained by how readily available families perceive such services within their communities. Speech and language therapies are available on-site in most schools while behavior support services are generally provided in off-site clinics or through privately contracted professionals in the home. As noted previously, it is generally preferable for children to receive early intervention services in the home; however, within rural communities this can be particularly challenging. Qualified professionals often reside considerable distances from rural families, requiring significant travel time for service provision (Meadan, Meyer, Snodgrass, & Halle, 2013; Mello et al., 2016). There is also variability in the types of service providers more easily accessible within communities. Speech language pathologists (SLPs) are more prevalent across both rural and metropolitan regions while board-certified behavior analysts (BCBAs) are more representative in nonrural areas (Mello et al., 2016). It is possible that this discrepancy is explained by BCBA being a relatively new profession in comparison to SLP, and thereby BCBAs have a less widespread presence than SLPs (Mello et al., 2016).

To counter these challenges, video-, teleconferencing, and other internet-based technologies are increasingly used to train educators and caretakers within rural communities on how to implement best practices at home and in the classroom (Boisvert, Lang, & Andrianopoulos, 2010; Gibson, Pennington, Stenhoff, & Hopper, 2010; Meadan, Meyer, Snodgrass, & Halle, 2013). Such “telehealth” methods are also useful for service providers to observe, assess, or screen a child remotely, and develop plans and interventions regarding his or her behavior, communication, and/or academic success (Gibson et al., 2010). While these pathways to service and consultation certainly have limitations, they offer the potential for meaningful access to rural communities that otherwise might have very little.

Ethnic and Racial Disparities in Access to Diagnosis and Support Services

Although there is no evidence that suggests racial or ethnic differences in either incidence or prevalence of ASD either in the United States or globally (Bertrand et al., 2001; Mandell, Listerud, Levy, Pinto-Martin, 2002), researchers have consistently found racial and ethnic variation in the rates of ASD diagnosis and documentation of ASD (Liptak et al., 2008; Magaña, Lopez, Aguinaga & Morton, 2013; Mandell et al., 2009; Zuckerman et al., 2014). For instance, Mandell et al. (2009) reported that non-White children (i.e., African American, Hispanic, Asian and other ethnicities) were less likely than White children to have documentation of an ASD diagnosis.

Furthermore, while the prevalence of having documentation of an ASD diagnosis was consistently lower for African American children than for White children across children of all IQ levels, in Hispanic and Asian populations, the disparity in documentation was even greater among children with IQs lower than 70 (Mandell et al., 2009).

Mandell et al. (2002) discussed the reasons why early diagnosis and having accurate documentation of ASD are essential. First, early interventions in response to timely diagnosis have demonstrated positive changes in children's development outcomes as many interventions are considered more effective with younger children (Vivanti et al., 2016). Second, due to the heightened risk of having a subsequent child with ASD, parents stand to derive substantial benefit from early diagnosis of their first child. Third, the Individuals with Disabilities Act (PL 94-142) mandates the public education system to provide children with special education and related services. Early identification is important to give time for schools to properly plan to provide FAPE to eligible students.

Early diagnosis is also important because the current healthcare system requires documentation of diagnosis in order to access mental health-related and psychiatric services. For example, children with ASD who lived in regions with low percentages of White residents were less likely to use psychotropic medications than children with ASD who lived in regions with high percentages of White residents (Mandell et al., 2009). Magaña et al. (2013) reported that Latino families received significantly fewer special services such as children's recreational programs, psychological services, family support services (respite), or intensive autism therapy than White families and voiced the need for improvements in such unmet services. Furthermore, Latino families with limited English proficiency more frequently reported experiencing barriers related to ASD knowledge, lower trust in service providers, and fewer therapy hours than non-Latino White families (Zuckerman et al., 2017).

Latino children with ASD are diagnosed later (2.5 years later) and less frequently than non-Latino White children with similar clinical autistic symptoms (Mandell et al., 2002; Zuckerman et al., 2014). However, when diagnosed, Latino children with ASD have been shown to have more severe autistic symptoms than non-Latino White children (Mandell et al., 2002). Relatedly, Mandell et al. (2002) also reported that African American children with ASD receive a diagnosis at older ages and are more likely to be misdiagnosed as having a conduct disorder or adjustment disorder than White children, while Latino children are more likely to be misdiagnosed as having specific language impairment.

Taken together, these reports indicate that lower rates of ASD diagnosis and delayed diagnosis among ethnic and racial minorities can be explained by contextual or environmental factors rather than clinical presentation. Differences in access to support or advocacy systems, cultural differences such as conceptualization of ASD among non-White parents (Zuckerman et al., 2014), language barriers, families' and school authorities' interpretations of symptoms, lack of awareness of available services, and absence of services or institutions that provide culturally sensitive support (Alegría et al., 2007) have all been cited as limitations in providing proper diagnostic services to ethnic and racial minorities.

Meanwhile, Smedley et al. (2003) attribute ethnic and racial disparities to federal laws and policies controlling healthcare provision. For instance, immigration status has been highlighted as a potential factor in the racial and ethnic disparities in diagnosis and service provision. Latino families with children with ASD voiced that they were unwilling to visit healthcare facilities due to fear of exposing their immigration status (Alegría et al., 2007). Furthermore, Fountain and Bearman (2011) reported that when policies protecting client privacy in regards to immigration status were in place in California, the rates of ASD diagnosis of Latino children and White children were similar, but when they were not in place, the rates of ASD diagnosis of Latino children were significantly lower than those of White children. Therefore, the underrepresentation of ASD among minority populations is also susceptible to the effects of state and federal immigrant policies (Fountain and Bearman 2011; Mandell et al., 2002).

Implications

In the Standards for Culturally and Linguistically Appropriate Services, the U.S. Department of Health and Human Services (DHHS) Office of Minority Health (OMH) instructed healthcare institutions to consider healthcare as “a cultural construct, arising from beliefs about the nature of disease and the human body” and cultural issues as “central in the delivery of health services treatment and preventive interventions” (U.S. DHHS, 2010, p. 80863 as cited in Smedley et al., 2003). Therefore, because culture and language influence how health is conceptualized, and how healthcare supports are provided and received, Smedley et al. (2003) have argued that increased responsiveness to culture and language will improve the quality of care not only for minority patients but all patients.

While more state and federal guidelines are requiring healthcare systems to be sensitive to the growing diversity of U.S. healthcare consumers, Smedley et al. (2003) offer additional recommendations for alleviating ethnic and racial disparities. For instance, they urge healthcare institutions, legislators, and regulators to develop policies that (a) bolster stable healthcare provider-patient relationships (e.g., accessibility of primary care providers, reasonable patient loads for primary physicians), (b) increase the proportion of healthcare professionals who are ethnic and racial minorities, (c) provide more funding and resources to the U.S. DHHS Office of Civil Rights to address and enforce civil rights laws, and (d) equalize access to insurance plans by encouraging public healthcare insurance programs like Medicare to provide higher quality plans to ethnic and racial minorities.

Conclusion

In the United States, federal law provides for diagnostic and support services for eligible children with ASD and their families. However, these services are not distributed equally across a variety of demographic variables including race, ethnicity,

immigration status, and geographic location. Health insurance and educational systems should cover the costs of services deemed necessary, but there are wide variations by state. Healthcare workers and other support providers should be aware these disparities and develop and implement policies that will mitigate these effects.

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