

Summer 2020

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Recommended Citation

Jacqueline Safstrom & Jennifer Safstrom *The Health and Legal Implications of Early Screening for Developmental Disabilities*, 29 *Annals Health L.* 153 (2020).

Available at: <https://lawcommons.luc.edu/annals/vol29/iss2/5>

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The Health and Legal Implications of Early Screening for Developmental Disabilities

*By: Jacqueline Safstrom & Jennifer Safstrom**

INTRODUCTION

Child development is a multifaceted process and there are certain milestones to reach that are imperative for healthy, timely growth and development.¹ Developmental monitoring, screening, and testing can aid in the identification, examination, and follow-up of a child's progress.² However, there are a plethora of barriers which inhibit a child's ability to access and receive adequate, quality care.³ These broader factors, or social determinants of health, can lead to an underutilization of preventive health services, causing a delay in early identification and intervention for children.⁴ This can have serious, adverse repercussions, because targeting interventions among children from birth to five years old is the most impactful time to

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1. *Milestone Checklist*, CTRS. FOR DISEASE CONTROL & PREVENTION, www.cdc.gov/ncbddd/actearly/pdf/checklists/Checklists-with-Tips_Reader_508.pdf (last visited Apr. 5, 2020).

2. *Developmental Monitoring and Screening*, CTRS. FOR DISEASE CONTROL & PREVENTION, www.cdc.gov/ncbddd/childdevelopment/screening.html (last visited Apr. 5, 2020).

3. *Access to Health Services Across Life Stages*, OFF. OF DISEASE PREVENTION & HEALTH PROMOTION, www.healthypeople.gov/2020/leading-health-indicators/2020-lhi-topics/Access-to-Health-Services/determinants (last visited Apr. 5, 2020).

4. *Id.*

make effective changes in a child's development.⁵

A family may experience a range of barriers to care, including limited health literacy, insufficient financial access, or fear of stigma. These issues impact access to insurance, willingness to seek care, and treatment or service options. Even when an individual can access care, other challenges, such as a lack in continuity of care or limited access to long-term services, can impede a child from accessing the support and interventions critical for their development. Without satisfactory development, a child is more likely to encounter educational challenges and legal issues. From an early age, these setbacks continue to persist and build upon one another. This lack of early detection further limits a child's ability to overcome said challenges and, in turn, results in poorer health outcomes, educational challenges, and increased legal troubles.

It is imperative to not only address and improve the lack of early developmental monitoring, but to also improve the systems aiding and contributing to these negative outcomes. Health outcomes can be improved through provider education that prioritizes awareness of child development and cultural competency. Additionally, policy changes to expand access to insurance and care, as well as professional regulation and enforcement efforts could help improve health outcomes. Similarly, educational challenges can be addressed through systemic policy reform efforts, especially those that target existing disparities, ensuring access to quality classroom opportunities and limiting bias in disciplinary practices. These reforms are essential to prevent the spillover of these effects into the criminal sphere, where individuals with a disability are overrepresented in interactions with law enforcement, convictions, and carceral populations. There additional prospective reforms—ranging from sentencing reform to expungement efforts—that could serve to restore justice to the criminal legal system.

This paper traces the trajectory of a person through various stages of life and possible interactions with a variety of institutions. Part II assesses the importance of childhood developmental monitoring and early intervention services, particularly as they pertain to setting a child up for success. Part III delves deeper into the social determinants that impact a child's access to services, which in turn influence a child's health and developmental outcomes, as addressed in Part IV and educational opportunities, as explored in Part V. Finally, Part VI highlights how a lack of opportunity at the earliest stages of life can lead to higher rates of incarceration and justice-involvement, followed by a discussion of ideas for reform.

Understanding the Importance of Childhood Developmental Monitoring

5. *Birth to 5: Watch Me Thrive!*, U.S. DEP'T OF HEALTH & HUMAN SERVS., EARLY CHILDHOOD DEV., www.acf.hhs.gov/ecd/child-health-development/watch-me-thrive (last visited Apr. 5, 2020).

and Early Intervention Services

Child development encompasses the physical, cognitive, and social-emotional growth and change that children experience from birth through childhood.⁶ This progress is measured in developmental milestones based on the child's age; these are new signs that a child is expanding in their ability to learn, speak, behave, move, or play.⁷ The U.S. Centers for Disease Control and Prevention (CDC) has published a list of accepted developmental milestones and other public education materials regarding children's development.⁸

There are important developmental milestones that occur when an infant is as young as two months old, with respect to the baby's social-emotional, language/communication, cognitive (learning, thinking, problem-solving), and physical development.⁹ For example, if an infant is cooing, making gurgling sounds, and turning their head towards sounds, these are signs of healthy language and communication development.¹⁰ Similarly, signs that a baby is beginning to smile at others, can briefly calm themselves, or look for a parent are signals that a two-month-old infant has healthy social and emotional developmental responses for their age.¹¹ There may also be signs of concern if a child this age is not reacting to loud sounds, tracking people or objects in movement with their eyes, or touching their mouth with their hands.¹²

There are also many ways that adults can help children build these capacities. With a two-month-old infant, for instance, caregivers can engage with their baby, through cuddling, talking, and playing, during daily activities such as mealtime or bath time; responding enthusiastically and smiling when the baby makes noises; or placing a mirror in the crib so the baby can look at themselves.¹³ Although these developmental milestones change with age, they provide a consistent framework for assessing whether a child's development is on a healthy trajectory across domains.¹⁴

6. *Early Child Development*, WORLD HEALTH ORG., www.who.int/topics/early-child-development/en/ (last visited Apr. 5, 2020).

7. *CDC's Developmental Milestones*, CTRS. FOR DISEASE CONTROL & PREVENTION, www.cdc.gov/ncbddd/actearly/milestones/index.html (last visited Apr. 5, 2020).

8. *Id.*

9. *Milestone Checklist*, *supra* note 1.

10. *Id.*

11. *Id.*

12. *Id.*

13. *Id.*

14. *Your Child at 5 Years*, CTRS. FOR DISEASE CONTROL & PREVENTION, www.cdc.gov/ncbddd/actearly/pdf/checklists/CDC-LTSAE-Checklists-with-Tips-5year-P.pdf (last visited Apr. 5, 2020).

Developmental surveillance, also referred to as developmental monitoring, is the process of “observ[ing] how a child grows and changes over time and whether [a] child meets the typical developmental milestones” for their age.¹⁵ This surveillance is typically done by a child’s caregiver, such as a parent or grandparent, who regularly interacts with the child and can report on developmental progress, as opposed to developmental screening, which is most often conducted by someone with additional training, such as a child’s healthcare provider or teacher.¹⁶ A developmental screening is a standardized instrument, often a questionnaire or checklist, that is research-based; it “ask[s] questions about a child’s development, including language, movement, thinking, behavior, and emotions.”¹⁷ Compared with developmental monitoring, “[d]evelopmental screening is more formal . . . and normally done less often,” but should be completed if there are any concerns about a child’s progress.¹⁸ However, screenings may be recommended more frequently if a “child is at higher risk for developmental problems due to preterm birth, low birthweight, environmental risks like lead exposure, or other factors[.]”¹⁹ There are a range of developmental screening tools that help assess a child’s developmental progress.²⁰ These metrics only provide a snapshot of a child’s developmental status; but, by identifying these potential difficulties, screenings can indicate whether additional assessment or intervention is required. Developmental delays “that can be identified by screening programs include learning disabilities, speech or language problems, autism, intellectual disability, emotional/behavioral conditions, hearing or vision impairment, or attention deficit hyperactivity disorder.”²¹

A developmental evaluation is meant to “[i]dentify and diagnose developmental delays and conditions.”²² The evaluation is conducted by a “[d]evelopmental pediatrician, child psychologist, or other trained provider” for the purpose of developing a “specific treatment” plan and to determine if the “child qualifie[s] for early intervention.”²³ This detailed examination allows for targeted supports to be provided in response to the child’s needs. Early intervention encompasses the “services and supports” for infants and

15. *Developmental Monitoring and Screening*, *supra* note 2.

16. *Id.*

17. *Id.*

18. *Id.*

19. *Id.*

20. *Birth to 5: Watch Me Thrive!*, *supra* note 5.

21. Melissa Stoppler & William C. Shiel, *Developmental Screening - Critical for Every Child*, MEDICINET, www.medicinenet.com/developmental_screening_-_critical_for_every_child/views.htm (last visited Apr. 5, 2020).

22. *Developmental Monitoring and Screening*, *supra* note 2.

23. *Id.*

youth with developmental delays and disabilities.²⁴ These services and supports include speech therapy, physical therapy, and other types of services, which can have a significant impact on a child's ability to learn new skills, overcome challenges, and can increase a child's success in school and life."²⁵ Research indicates that early childhood intervention programs "yield benefits in academic achievement, behavior, educational progression and attainment, delinquency and crime, and labor market success, among other domains"²⁶ and that these interventions are "likely to be more effective when [...] provided earlier in life rather than later."²⁷

SOCIAL DETERMINANTS OF HEALTH & BARRIERS TO ACCESS

Despite the importance of developmental monitoring, screening, and testing, there are many barriers that can impede a child from receiving the appropriate level of care. These barriers are social, financial, and other systemic obstacles that can limit a child's access to the assessment and early intervention that would allow them to maximize their developmental outcomes over the long-term. Often it is these social determinants of health that, in turn, impact the access to care a child receives; these include "socioeconomic status, education, neighborhood and physical environment, employment, and social support networks, as well as access to health care."²⁸

Health literacy is defined as "the degree to which individuals can obtain, process, and understand the basic health information and services they need

24. *What is "Early Intervention"?*, CTRS. FOR DISEASE CONTROL & PREVENTION, www.cdc.gov/ncbddd/actearly/parents/states.html (last visited Apr. 5, 2020).

25. *Id.*

26. LYNN A. KAROLY ET AL., RESEARCH BRIEF: PROVEN BENEFITS OF EARLY CHILDHOOD INTERVENTIONS 1 (2005); *see, e.g., Overview of Early Intervention*, CTR. FOR PARENT INFO. & RES. (Sept. 1, 2017), www.parentcenterhub.org/ei-overview/ (summarizing the different early intervention services available).

27. *Why Act Early if You're Concerned about Development?*, CTRS. FOR DISEASE CONTROL & PREVENTION, www.cdc.gov/ncbddd/actearly/whyActEarly.html (last visited Apr. 5, 2020); *see, e.g., Study Reveals Prolonged Effectiveness of Early Intervention Program*, ROBERT WOOD JOHNSON FOUND. (Mar. 5, 2016), www.rwjf.org/en/library/articles-and-news/2006/03/study-reveals-prolonged-effectiveness-of-early-intervention-prog.html (discussing a study which found positive effects of early intervention programs).

28. Samantha Artiga & Elizabeth Hinton, *Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity*, HENRY J. KAISER FAM. FOUND. (May 10, 2019), www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity.

to make appropriate health decisions.”²⁹ It is estimated that approximately 90 million people, or half of the U.S. adult population, has “inadequate health literacy to navigate the health care system.”³⁰ Health information can be utilized by an individual to make healthier lifestyle choices, access preventive health measures, and better comprehend when and where to acquire medical care.³¹ When an individual has little to no health literacy, it has been linked to poorer health outcomes.³² Research studies have illustrated that the use of preventive services is extremely low among persons with limited health literacy.³³ This includes accessing provisions like annual physical exams, immunizations such as the flu shot, screenings for cholesterol or types of cancers, as well as mammograms and Pap smears.³⁴

Furthermore, limited health literacy skills lead to a delay in accessing care, with individuals entering into the healthcare system with more severe symptoms and further complications.³⁵ This in turn leads to the development of more chronic conditions, which persons with limited health literacy skills are not well equipped to effectively manage.³⁶ Patients with inadequate health literacy who are afflicted by conditions such as HIV/AIDS,³⁷ asthma,³⁸

29. MARIA HEWITT & Lyla M. HERNANDEZ, *IMPLICATIONS OF HEALTH LITERACY FOR PUBLIC HEALTH: WORKSHOP SUMMARY 1* (NAT’L ACADEMIES PRESS 2014).

30. *Id.*

31. *Quick Guide to Health Literacy*, U.S. DEP’T OF HEALTH & HUMAN SERVS., www.centralwestgippslandpcp.com/assets/files/pre-2019/projects/health-literacy/guide/Quickguide.pdf (last visited Apr. 5, 2020).

32. *Id.* at 7.2.

33. *Id.* at 6.1.

34. *Id.* at 3.1.

35. *Id.*

36. *Id.*

37. Seth C. Kalichman et al., *Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy*, 14 J. GEN. INTERNAL MED. 267, 272 (1999); Seth C. Kalichman & David Rompa, *Functional Health Literacy is Associated with Health Status and Health-Related Knowledge in People Living with HIV-AIDS*, 25 J. ACQUIRED IMMUNE DEFICIENCY SYNDROMES & HUMAN RETROVIROLOGY 337, 337–44 (2000); Seth C. Kalichman et al., *Health Literacy and Health-Related Knowledge Among Persons Living with HIV/AIDS*, 18 AM. J. PREVENTIVE MED. 325, 325–331 (2000).

38. Mark V. Williams et al., *Inadequate Literacy is a Barrier to Asthma Knowledge and Self-Care*, 14 CHEST 1008, 1008 (1998).

diabetes,³⁹ or hypertension⁴⁰ are less likely to be aware of their condition, have knowledge regarding said condition, and unable to satisfactorily manage their illness.⁴¹

Low or limited health literacy is correlated with “an increase in preventable hospital visits and admissions.”⁴² This includes higher rates of emergency room visits, utilization of emergency services, and hospitalization.⁴³ In addition, there is a “greater use of services designed to *treat* complications of disease and less use of services designed to *prevent* complications” among individuals with limited health literacy.⁴⁴ The increased usage of emergency services is linked with higher healthcare costs overall.⁴⁵

Further, low health literacy can lead to negative psychological effects.⁴⁶ A study on shame and health literacy, conducted by Parikh, et al., revealed that participants with low health literacy reported feeling shameful regarding their ability to comprehend health information.⁴⁷ Given this, it is common for individuals to mask their literacy challenges in order to avoid embarrassment

39. Dean Schillinger et al., *Association of Health Literacy with Diabetes Outcomes*, 288 J. AM. MED. ASSOC. 475, 481 (2002); Dean Schillinger et al., *Closing the Loop: Physician Communication with Diabetic Patients Who Have Low Health Literacy*, 163 INTERNAL MED. 83, 84 (2003).

40. Mark V. Williams et al., *Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Disease: A Study of Patients with Hypertension and Diabetes*, 158 INTERNAL MED. 166, 170 (1998).

41. *Quick Guide to Health Literacy*, *supra* note 31, at 3.1.

42. *Id.*; see David W. Baker et al., *The Relationship of Patient Reading Ability to Self-Reported Health and Use of Health Services*, 87 AM. J. PUB. HEALTH 1027, 1029 (1997) (writing that patients in Atlanta with low literacy were more likely to be hospitalized); see also David W. Baker et al., *Health Literacy and the Risk of Hospital Admission*, 13 J. GEN. INTERNAL MED. 791, 797 (1998) (writing that patients with inadequate literacy have poor health outcomes); see also David W. Baker et al., *Functional Health Literacy and the Risk of Hospital Admission Among Medicare Managed Care Enrollees*, 98 AM. J. PUB. HEALTH 1278, 1282 (2002) (writing that inadequate functional health literacy is associated with the risk of hospital admission); see also M.M. Gordon et al., *Illiteracy in Rheumatoid Arthritis Patients as Determined by the Rapid Estimate of Adult Literacy (REALM) Score*, 41 RHEUMATOLOGY 750, 752 (2002) (writing that illiterate patients reported three times as many out-patient clinic visits as literate patients).

43. *Quick Guide to Health Literacy*, *supra* note 31, at 2.3.

44. *Id.* at 3.2 (emphasis in original).

45. *Id.*

46. Nina Parikh et al., *Shame and Health Literacy: The Unspoken Connection*, 27 PATIENT EDUC. & COUNSELING 33, 37 (1997).

47. *Id.* at 38.

and preserve their dignity.⁴⁸

Limited health literacy can lead to lower enrollment in public welfare programs with complex and fragmented enrollment processes, with parents facing additional barriers to access care for themselves and their dependents, which is predictive of racial disparities in child health insurance enrollment.⁴⁹ Based on research conducted by Jimenez and colleagues in 2013, there are four identified primary themes based on parents' health literacy level.⁵⁰ The first is a lack of continuity with a single provider, making the level of care received by dependents disjointed, low-quality, and infrequent.⁵¹ Second, respondents expressed difficulty communicating and learning about available resources and programs, such as early intervention services (EI).⁵² Third, parents stated confusion regarding program requirements or the referral process when trying to attain services.⁵³ Finally, many parents conveyed poor communication by their pediatrician, who did not take the time to verbally explain diagnoses or treatment plans.⁵⁴ Written materials proved unhelpful, as some patients were illiterate and felt shame in making this fact known to their health care provider.⁵⁵

Another significant barrier to accessing care, for many, is lack of health insurance and financial resources. Health insurance allows individuals to access health care services stretching from preventive services to management of health conditions.⁵⁶ Inequality in health insurance coverage is interrelated to incongruences in access and quality of care. Other factors and circumstances are entwined with financial barriers and lack of insurance. For example, "too few providers in a community, long travel times to the nearest provider, and practitioners who do not speak the language or understand the culture of their patients" perpetuate health disparities and unfairly impacts people of color, individuals with low socioeconomic status,

48. *Id.*; David W. Baker et al., *The Health Care Experience of Patients with Low Literacy*, 5 *FAM. MED.* 329, 329 (1996).

49. Manuel Jimenez et al., *The Impact of Parental Health Literacy on the Early Intervention Referral Process*, 24 *J. HEALTH CARE FOR POOR & UNDERSERVED* 1053, 1054 (2013).

50. *Id.* at 1055.

51. *Id.*

52. *Id.* at 1055–56.

53. *Id.* at 1056.

54. *Id.*

55. *Id.*

56. E. RICHARD BROWN ET AL., *UCLA CTR. FOR HEALTH POL'Y & HENRY J. KAISER FAM. FOUND., RACIAL AND ETHNIC DISPARITIES IN ACCESS TO HEALTH INSURANCE AND HEALTH CARE* 8 (2000).

and those who are not native English speakers.⁵⁷

When analyzing wage loss among guardians who take time off from work to seek care for their sick child, it has been reported that the “mean wage loss was \$343/missed work day, and families also incurred mean additional costs of \$156 in the past year due to children’s illnesses.”⁵⁸ Transportation can be a significant barrier to care, especially for individuals relying on public transit,—which may or may not be reliable and can become costly when accounting for multiple trips to providers.⁵⁹

Estimates indicate that there are 4.8 million (6 percent) adolescents in the United States of America that are uninsured.⁶⁰ Of this group, 3.3 million (68 percent) of children are eligible for Medicaid/Children’s Health Insurance Program (CHIP), however they are not enrolled.⁶¹ Minority children constitute the highest uninsured rates in the U.S., with an estimation that 2.4 million (53 percent) uninsured American adolescents are Latino and African American.⁶² Among this subpopulation, approximately 1.6 million children are eligible for Medicaid/Children’s Health Insurance Program (CHIP) but are not enrolled.⁶³ Lack of insurance translates into higher medical care costs for individuals and families, which in turn leads to lower levels of preventive care utilization and higher rates of emergency services usage.⁶⁴ Loss of health insurance is frequently a result of the insurance expiring without the individual being aware, and roughly one-third of the cases did not reapply.⁶⁵

A lack of financial stability has shown to further negatively impact low-income families in accessing and attaining care.⁶⁶ In a cross-sectional study conducted by Flores, there were more than 260 participants included to examine “parental awareness of and reasons for lack of health insurance

57. *Id.*; see also Jimenez et al., *supra* note 49, at 1058 (discussing parents’ experiences with early intervention programs who had low health literacy).

58. Glenn Flores et al., *A Cross-Sectional Study of Parental Awareness of and Reasons for Lack of Health Insurance Among Minority Children, and the Impact on Health, Access to Care, and Unmet Needs*, 15 INT’L J. FOR EQUITY IN HEALTH, 2016, at 6 [hereinafter Flores et al., *Cross-Sectional Study*].

59. Samina Syed et al., *Traveling Towards Disease: Transportation Barriers to Health Care Access*, 38 J. CMTY. HEALTH 976, 979 (2013).

60. Flores et al., *Cross-Sectional Study*, *supra* note 58, at 2.

61. *Id.*

62. *Id.*

63. *Id.*

64. Glenn Flores et al., *The Health and Healthcare Impact of Providing Insurance Coverage to Uninsured Children: A Prospective Observational Study*, 17 BIOMED CENT. PUB. HEALTH 1, 8-9 (2017) [hereinafter Flores et al., *Observational Study*].

65. Flores et al., *Cross-Sectional Study*, *supra* note 58, at 3.

66. See *id.* at 7 (discussing the impact of a lack of insurance on Medicaid and CHIP-eligible populations).

among minority children, and the impact on health, access to care, and unmet needs.⁶⁷ In this study, 50 percent of the participants reported requiring supplemental income to cover children's medical expenses.⁶⁸ Additionally, 25 percent of parents indicated they took time off work in order to obtain healthcare for their children and 10 percent stated they terminated their employment as a result of their child's health.⁶⁹ More than one-third of parents specified that familial financial problems resulted due to their child's health.⁷⁰

Lacking a primary care provider as well as visiting a multitude of providers significantly reduces the quality of care a child receives.⁷¹ The Flores study discovered that among study participants, two-thirds of children had no primary care provider.⁷² Moreover, 40 percent had no usual source for preventive care and more than half indicated having multiple sources for preventive and sick care.⁷³ Additionally, prioritization is another significant barrier to accessing healthcare for many Americans. There is a lack of awareness among the U.S. population regarding developmental wellness and the importance of early screening and intervention.⁷⁴ Not realizing the long-term impacts that can result from a child lacking or never receiving these critical services can be significantly damaging.

Compounding the negative effects of inconsistent, piecemeal care and a lack of prioritization, stigma plays a large role in preventing people from attaining routine, quality care, whether because of culture, prior negative experiences, or other reasons.⁷⁵ In some communities, there is stigma associated with receiving health services.⁷⁶ Some may believe that being "sick" is narrowly defined as being physically ill—such as coughing, sneezing, etc.⁷⁷ This stigma leads to individuals avoiding annual checkups or

67. *Id.* at 1.

68. *Id.* at 6.

69. *Id.*

70. *Id.* at 9.

71. Flores et al., *Observational Study*, *supra* note 64, at 5.

72. *Id.* at 3.

73. *Id.* at 3-4.

74. Jennifer Johnson, *Raising Awareness about Developmental and Behavioral Screening*, ADMIN. FOR CMTY. LIVING (Oct. 10, 2014), acl.gov/news-and-events/acl-blog-events-and-observances/raising-awareness-about-developmental-and.

75. Katharine E. Zuckerman et al., *Racial, Ethnic, and Language Disparities in Early Childhood Developmental/Behavioral Evaluations: A Narrative Review*, 53 REV. CLINICAL PEDIATRICS 619, 623 (2014).

76. *Id.*

77. *See id.* (writing that minority parents may be more distrustful in medicine generally).

obtaining specialty services, such as mental health care.⁷⁸ Additionally, this creates a gap in early diagnosis and treatment of childhood developmental and behavioral conditions.⁷⁹ Studies have shown that “African American and Latino children are less likely to be diagnosed with an autism spectrum disorder (ASD), and are more likely to be diagnosed at older ages and with more severe symptoms.”⁸⁰ In regard to mental health care, it is often times perceived negatively and is extremely stigmatized.⁸¹ For minority children, who face significant challenges regarding access and insurance coverage, there are numerous “unmet needs for mental health care [which] are high and [access to care] may be particularly unavailable.”⁸²

Lastly, language is a noteworthy and crucial barrier to care. Language barriers have been reported to be a leading cause as to why uninsured children have never been or are never enrolled in health insurance, following the high cost associated with having insurance.⁸³ Non-English speakers and individuals with limited English proficiency can experience difficulty understanding and communicating with their providers.⁸⁴ This in turn leads to reduced health literacy and access to care that is culturally and linguistically responsive.⁸⁵

HEALTH CONSEQUENCES

Early childhood has been identified as the most impactful time period to guarantee that a child reaches and develops their full potential.⁸⁶ The time between birth and five years of age “is critical for the development of language, cognitive, emotional, social, behavioral, and physical skills.”⁸⁷ Focusing on this age-group and honing interventions to directly target children under five years old is imperative in reducing the number of individuals afflicted by developmental disorders and delays. These disorders can range from “subtle learning disabilities to severe cognitive/motor impairment.”⁸⁸ Timely intervention relies heavily on the early recognition

78. *Id.* at 622.

79. *Id.* at 619.

80. *Id.*

81. *Id.* at 623.

82. *Id.* at 624.

83. Flores et al., *Cross-Sectional Study*, *supra* note 58, at 3.

84. Yolanda Partida, *Medicine and Society Language Barriers and the Patient Encounter*, 9 AM. MED. ASS'N J. ETHICS 566, 566–71 (2007).

85. Flores et al., *Cross-Sectional Study*, *supra* note 58, at 7-8.

86. Mehpare Ozkan et al., *The Socioeconomic and Biological Risk Factors for Developmental Delay in Early Childhood*, 171 EUROPEAN J. PEDIATRICS 1815, 1816 (2012).

87. *Id.*

88. *Id.*

and detection of developmental problems.⁸⁹ However, only 30 percent of such cases are identified before a child begins school.⁹⁰

It is imperative that primary care physicians possess specific competencies critical to discussing patient care, especially for serving patients with developmental disabilities. First, possessing a strong level of medical knowledge regarding developmental disabilities is necessary in order to provide quality care.⁹¹ This not only entails having familiarity with characteristics and symptoms of developmental disorders, but also being able to “recognize that there are differences in ability levels of specific individuals who share developmental conditions.”⁹² Knowledge in combination with work experience can bolster a physician’s capabilities significantly, affording them the opportunity to be exposed to a plethora of situations.

Second, patient feedback in various studies has indicated how essential a provider’s compassion and sensitivity is when receiving care.⁹³ Key competencies which health care providers should possess are “compassion, good listening skills, and maintaining flexibility.”⁹⁴ A provider’s awareness regarding the day-to-day difficulties faced by those with developmental disabilities and what accommodations are necessary can allow for better care to be provided.

Third, strong observational and communication skills have been identified as impactful capabilities for providers to have when treating patients.⁹⁵ This competency is even more important when treating and caring for patients who may be illiterate, nonverbal, or hearing impaired.⁹⁶ The U.S. Bureau of the Census reported that “of the more than 37 million adults in the U.S. who speak a language other than English, some 18 million people—48 percent—report that they speak English less than ‘very well.’”⁹⁷ Communication and language barriers are largely linked to lower utilization of health resources, mainly preventive services, as well as lower quality of care provided.⁹⁸ Not only are services underutilized, patients also report lower levels of satisfaction, limited comprehension, and inadequate adherence to treatment

89. *Id.*

90. *Id.*

91. HARDER + CO., A BLIND SPOT IN THE SYSTEM: HEALTH CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES i (2008).

92. *Id.* at 7.

93. *Id.* at 8.

94. *Id.*

95. *Id.*

96. *Id.*

97. *Cultural Competence in Health Care: Is it Important for People with Chronic Conditions?*, GEORGETOWN UNIV., HEALTH POL’Y INST., hpi.georgetown.edu/cultural/ (last visited Apr. 5, 2020).

98. *Id.*

regimens.⁹⁹

Fourth, medical providers should “have an understanding of the complex system of agencies that support people with developmental disabilities.”¹⁰⁰ Providers can serve as a wonderful source for patients to learn about external resources and organizations that they can benefit from. By being aware of other services, health care providers can assist with bridging communication between organization and patient to seamlessly coordinate services.

Lastly, cultural competence and patient centeredness are approaches which are vital in order to deliver high-quality, holistic, and effective care to patients. With the rapid pace of migration and the rich diversity of communities, the need for a workforce that is adept and culturally sensitive is more important than ever. Cultural competence is defined “as the ability of providers and organizations to effectively deliver health care services that meet the social, cultural, and linguistic needs of patients.”¹⁰¹ As discussed previously, racial and ethnic minorities are disproportionately impacted by higher rates of morbidity and mortality.¹⁰² A culturally competent health care workforce can result in “improve[d] health outcomes and quality of care, and can contribute to the elimination of racial and ethnic health disparities.”¹⁰³ Additional measures which can be integrated into already existing health care systems are providing interpreter services, utilizing community health workers, “incorporate culture-specific attitudes and values into health promotion tools,” and offering cultural competence trainings for staff.”¹⁰⁴

One potential solution with regards to accessing regular, quality care is expanding and advancing the utilization and availability of telemedicine. Telemedicine “has the potential to build capacity among caregivers and local providers as well as promote family-centered services through remote consultation.”¹⁰⁵ Telemedicine has been shown to reduce the gap between necessary interventions and the resources which are available.¹⁰⁶ This feasibility is based on the premise that professional medical services can be provided to individuals at a distance, mainly via video streaming platforms.¹⁰⁷ One main benefit of telemedicine, in addition to the low cost of essential equipment, is that it is a service that is accessible regardless of the time of

99. *Id.*

100. HARDER + CO., *supra* note 91, at 8.

101. *Cultural Competence in Health Care, supra* note 97.

102. *Id.*

103. *Id.*

104. *Id.*

105. Jana Cason, *Telerehabilitation: An Adjunct Service Delivery Model for Early Intervention Services*, 3 INT’L J. TELEREHABILITATION 19, 22 (2011).

106. *Id.*

107. *Id.* at 23.

day or location of a patient.¹⁰⁸ Furthermore, by reducing the delay in attaining medical attention, individuals are able to access services and treatment sooner than before.¹⁰⁹ This is especially true for accessing specialty providers and services which may not be available within a local community.¹¹⁰ The distance to a medical provider, transportation complications, and lack of time are all non-issues when considering telemedicine for health care access.¹¹¹ Moreover, the same case can be made for attaining medical care in the native language of the patient. By utilizing telemedicine, there is the ability to connect patients to providers who speak their native language. A patient's ability to communicate confidently and comfortably with their provider is vital to ensuring quality care is given. Telemedicine is a newly emerging and highly impactful service delivery model which can be employed to "more efficiently disseminate evidence-based practices into community settings."¹¹² It offers a solution to people who are geographically and economically compromised by allowing them to attain treatment and receive a superior level of care.

Another prospective solution would be to pursue litigation against physicians who fail to comply with recommended screening timelines and protocols, as the American Academy of Pediatrics (AAP) recommendations guide health care providers to do.¹¹³ The AAP advises that "developmental surveillance [be conducted] at every health supervision visit and conducting general developmental screening using evidence-based tools at 9, 18, and 30 months, or whenever a concern is expressed . . . and social-emotional screening is recommended at regular intervals."¹¹⁴ Yet, it is likely doctors are falling short of this requirement. A 2002 AAP study of Periodic Survey of Fellows found fewer than 25 percent of respondents consistently used

108. Laurie A. Vismara et al., *Preliminary Findings of a Telehealth Approach to Parent Training in Autism*, 43 J. AUTISM & DEVELOPMENTAL DISORDERS 2953, 2953 (May 17, 2013).

109. *Id.*

110. *Id.* at 2954.

111. *Id.* at 2967.

112. Katherine E. Pickard et al., *A Mixed-Method Evaluation of the Feasibility and Acceptability of a Telehealth-Based Parent-Mediated Intervention for Children with Autism Spectrum Disorder*, 20 AUTISM 845, 845 (2016).

113. AM. ACAD. PEDIATRICS, *Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening*, 118 PEDIATRICS 405, 407 (2006).

114. *Id.* at 409-414; see generally *Screening Recommendations*, AM. ACAD. PEDIATRICS, www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/Screening-Recommendations.aspx (last visited Apr. 5, 2020) (providing general information regarding screening).

appropriate screening tools.¹¹⁵ As such, pursuing physician liability claims, particularly under a negligence standard, or modifying credentialing and re-certification requirements for physicians could help ensure compliance with these recommendations that, in turn, would help promote optimal early childhood development.¹¹⁶ Through increased prioritization and stricter enforcement within the profession, as part of credentialing standards or continuing medical education coursework, the medical community could also make efforts to enhance compliance with these guidelines.

EDUCATIONAL CONSEQUENCES

Developmental wellness is also essential to educational success, and developmental challenges can have debilitating consequences on a child's learning, even from an early age. However, these setbacks can have a long-term negative impact on learning, especially once a child reaches schooling age. These educational delays and challenges can have a compounding effect. As such, it is important to understand how a lack of diagnosis can disrupt a child's education in early childhood education settings, at school, and beyond the classroom.

Lack of access to quality learning opportunities is one such barrier to developmental wellness. Typically care for pre-school age children is referred to as "child care," which encompasses the child's safety and wellbeing, including that they are clean, fed, and cared for.¹¹⁷ However, this term does not account for the learning and development that occurs during these critical years.¹¹⁸ Although it is far harder to assess if a child is being appropriately engaged in age-appropriate learning activities, "research continues to affirm the short- and long-term benefits for children who participate in high-quality early learning programs."¹¹⁹ Environments that are more likely to maximize a child's healthy development—settings that are

115. Linda Radecki et al., *Trends in the Use of Standardized Tools for Developmental Screening in Early Childhood: 2002–2009*, 128 *PEDIATRICS* 14, 14-19 (2013).

116. AM. ACAD. PEDIATRICS & BRIGHT FUTURES, *RECOMMENDATIONS FOR PREVENTIVE PEDIATRIC HEALTH CARE (PERIODICITY SCHEDULE)* (2019), downloads.aap.org/AAP/PDF/periodicity_schedule.pdf.

117. See, e.g., SIMON WORKMAN & REBECCA ULLRICH, *QUALITY 101: IDENTIFYING THE CORE COMPONENTS OF A HIGH-QUALITY EARLY CHILDHOOD PROGRAM 1* (Ctr. for Am. Progress, 2017), www.americanprogress.org/issues/early-childhood/reports/2017/02/13/414939/quality-101-identifying-the-core-components-of-a-high-quality-early-childhood-program/ (suggesting generally that basic care for preschool aged children consists of ensuring they are fed and cared for on a basic level).

118. *Id.* at 2.

119. *Id.* at 1.

secure, engaging, and nurturing—typically include highly trained educators with prior experience who are recruited and retained in the profession, where there is low staff turnover, and where there are low child/teacher ratios.¹²⁰ Quality early learning opportunities provide children with a “a profound, lifelong advantage,” as research shows they are less likely to be involved with the criminal legal system or struggle with substance abuse, and are more likely to graduate high school and college.¹²¹ Yet, the cost of care is staggering: “[i]n 40 states the average annual cost for an infant in center-based care was higher than a year’s tuition and fees at a four-year public college.”¹²² As a result, center-based child-care and after-school care is highly unaffordable for parents, regardless of whether they work full-time, and consumes a large proportion of family income.¹²³ Researchers noted that “Black and Hispanic parents are more likely to experience unaffordable child care” as compared with other groups.¹²⁴

Worse still, early education “caregivers make poverty wages” and “only a handful of centers and family homes are nationally accredited for quality.”¹²⁵ Even for those who are able to find affordable, quality care, educational pushout¹²⁶ begins at this age and can contribute over the long-term to student school dropout. For instance, according to the U.S. Department of Education, Black students are significantly overrepresented in preschool suspensions,

120. *Id.* at 7; *Child Care Quality*, CHILD CARE SERVS. ASSOC., www.childcareservices.org/families/fs/finding/child-care-quality (last visited Apr. 5, 2020).

121. Kelsey Piper, *Early Childhood Education Yields Big Benefits—Just Not the Ones You Think*, VOX (Oct. 16, 2018, 9:00 AM), www.vox.com/future-perfect/2018/10/16/17928164/early-childhood-education-doesnt-teach-kids-fund-it.

122. *See* Lisa Belkin, *Child Care Costs More Than College*, N.Y. TIMES (Aug. 9, 2010, 11:22 AM), parenting.blogs.nytimes.com/2010/08/09/child-care-costs-more-than-college (noting that in the past decade “the cost of child care for the youngest children increased twice as fast as the median family income throughout the country, and in half the states it far outpaced the rate of inflation”).

123. Maura Baldiga et al., *Child Care is Unaffordable for Working Parents Who Need It Most*, NAT’L INST. FOR EARLY EDUC. RESEARCH, GRADUATE SCHOOL EDUC., RUTGERS UNIV. (Feb. 15, 2019), <http://nieer.org/2019/02/15/child-care-is-unaffordable-for-working-parents-who-need-it-most>.

124. *Id.*

125. Brigid Schulte & Alieza Durana, *Overview: The Care Report*, NEW AM. (Sept. 28, 2019), www.newamerica.org/in-depth/care-report/introduction/.

126. “Pushout refers to practices that contribute to students dropping out. These include unwelcoming and uncaring school environments and over-reliance on zero tolerance school policies that push students out of school.” *Pushout*, NAT’L CLEARINGHOUSE ON SUPPORTIVE SCH. DISCIPLINE, <https://supportiveschooldiscipline.org/learn/reference-guides/pushout> (last visited May 4, 2020).

comprising nineteen percent of the total preschool population but forty-seven percent of suspensions.¹²⁷ It is not hyperbole to state that “[t]he school to prison pipeline starts in preschool,” as implicit bias leads early education staff to observe Black students more closely, and thus the trend of funneling children out of educational setting to the criminal legal system starts at this age.¹²⁸

These difficulties can continue, or be further magnified, in the school setting. Under the Individuals with Disabilities Education Act (IDEA), local school districts must “identify, locate, and evaluate every child who may have a disability requiring special education services.”¹²⁹ Under this legal mandate, known as “Child Find,” parents have a right to request and educators have the responsibility to request a full, individual, comprehensive, multi-disciplinary evaluation.¹³⁰ This obligation extends to all students, regardless of their educational setting; this means that those in private schools or receiving homeschooling services are included.¹³¹ A student with a disability, under the IDEA, is a child evaluated as having an intellectual disability, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as “emotional disturbance”), an orthopedic impairment, autism, traumatic brain injury, other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services.¹³²

When a student is identified as in need of special education services, the school’s interdisciplinary team must develop an Individualized Education Plan (IEP), which includes documentation of the student’s “‘present levels of academic achievement and functional performance;’ ‘measurable annual goals’; and ‘special education and related services and supplementary aids and services.’”¹³³

127. 2013-2014 CIVIL RIGHT DATA COLLECTION A FIRST LOOK: KEY DATA HIGHLIGHTS ON EQUITY AND OPPORTUNITY GAPS IN OUR NATION’S PUBLIC SCHOOLS, U.S. DEP’T OF EDUC.: OFF. FOR CIV. RTS. (Oct. 28, 2016), www2.ed.gov/about/offices/list/ocr/docs/2013-14-first-look.pdf.

128. *The School-to-Prison Pipeline Starts in Preschool*, SCHOTT FOUND. FOR PUB. EDUC.: BLOG POST (Oct. 24, 2016), schottfoundation.org/blog/2016/10/24/school-prison-pipeline-starts-preschool.

129. Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

130. Blakely Simoneau, *Special Education in American Prisons: Risks, Recidivism, and the Revolving Door*, 15 STAN. J. CIV. RTS. & CIV. LIBERTIES 87, 101–02 (2019).

131. *Id.* at 101.

132. 34 C.F.R. § 300.8 (2012).

133. *Id.* at 101–02 (quoting 34 C.F.R. § 300.320(a)(1)– (4)).

While a diagnosis can provide access to services and important protections, students with disabilities, particularly students of color with a diagnosis, have disproportionately poorer outcomes as compared with their peers.¹³⁴ Students of color with disabilities continue to face forms of discrimination that are at times in tension with one another. For instance, Black students are simultaneously over-identified and under-identified as having disabilities.¹³⁵ Black students are over diagnosed “because academic performance or behaviors that may be a reflection of inadequate instruction or the highly subjective judgments of school staff are instead pathologized as signs of a disability.”¹³⁶ Conversely, Black students at the same time are under-identified when classroom shortcomings are “attributed to personal or cultural failings,” rather than the need for intervention.¹³⁷

These tensions are amplified in the discipline context. When a youth commits an offense at school, the student’s misconduct can be dealt with in one of three ways: “within the school itself, through a juvenile court proceeding, or in an adult criminal court.”¹³⁸ The “school-to-prison pipeline” refers to the process through which a student is pushed out of the school system and into the criminal legal system, as a school’s disciplinary policies and practices increase contact with law enforcement officers, criminalize conduct, and brand students as “offenders” from a young age.¹³⁹ The school-to-prison pipeline has been reinforced by the adoption of “zero-tolerance policies, additional and often mandatory referral of students to the juvenile justice system, and the expanding prevalence of ‘school resource officers’ (SROs) in schools.”¹⁴⁰

Students of color and students with disabilities are both disproportionately subject to school punishment, including suspensions and expulsions, but “this disparity is compounded for students of color with disabilities.”¹⁴¹ Research shows that although rates of misconduct are similar, “Black students are disproportionately disciplined for more subjective offenses, such as disrespecting a teacher or being perceived as a threat, than their White

134. Alice Abrokwa, “*When They Enter, We All Enter*”: *Opening the Door to Intersectional Discrimination Claims Based on Race and Disability*, 24 MICH. J. RACE & L. 15, 44 (2018).

135. *Id.* at 43.

136. *Id.*

137. *Id.*

138. Tara Carone, *The School to Prison Pipeline: Widespread Disparities in School Discipline Based on Race*, 24 PUB. INT. L. REP. 137, 143 (2019).

139. *Id.*

140. *Id.*

141. Abrokwa, *supra* note 134.

counterparts.”¹⁴² Similarly, students with disabilities are also overrepresented in police interactions as compared to their nondisabled peers, as students with disabilities represent one-fourth of school-related arrests and referrals to law enforcement, despite comprising “just 12 percent of the general student population.”¹⁴³

Constitutional protections available within the criminal legal system are not guaranteed in school disciplinary proceedings, including “the Eighth Amendment’s ban on cruel and unusual punishment . . . , the Fifth Amendment’s guarantee against self-incrimination and double jeopardy, and Sixth Amendment’s right to counsel and jury trial guaranteed.”¹⁴⁴ Rather, the U.S. Supreme Court established minimum due process requirements for students facing short-term suspension in *Goss v. Lopez*.¹⁴⁵ The Court held “that the student [must] be given oral or written notice of the charges against him and, if he denies the charges, an explanation of the evidence the authorities have and an opportunity to present his side of the story.”¹⁴⁶ The IDEA established additional protections for students with disabilities, including requiring school officials to conduct “manifestation review” that determines “whether the behavior is a manifestation of the child’s mental illness.”¹⁴⁷ The IDEA also requires that during a manifestation review or due process hearing for disciplinary action, the child cannot be expelled and must “remain in their current educational placement.”¹⁴⁸ If the child’s behavior is

142. NAACP LEGAL DEFENSE & EDUC. FUND., *EXECUTIVE SUMMARY, LOCKED OUT OF THE CLASSROOM: HOW IMPLICIT BIAS CONTRIBUTES TO DISPARITIES IN SCHOOL DISCIPLINE* 4 (2017); see also NAT’L COUNCIL ON DISABILITY, *BREAKING THE SCHOOL-TO-PRISON PIPELINE FOR STUDENTS WITH DISABILITIES* 47 (2015) (discussing studies that show school administrators “dole out harsher punishment to students of color than white students for the same or similar behavior”); see also Russell J. Skiba et al., *The Color of Discipline: Sources of Racial and Gender Disproportionality in School Punishment*, 34 URB. REV. 317, 335 (2002) (writing that “significantly different patterns of referrals suggest that black students are more likely to be referred to the office for more subjective reasons”).

143. Claire Raj, *Disability, Discipline, and Illusory Student Rights*, 65 UCLA L. REV. 860, 863 (2018) (citing OFF. FOR CIV. RTS., U.S. DEP’T OF EDUC., *DATA SNAPSHOT: SCHOOL DISCIPLINE*, ISSUE BRIEF NO. 1 at 7 (2014)).

144. Carone, *supra* note 138, at 144.

145. *Id.*

146. *Id.*

147. Dominique Hadley, *Implementing School-Based Health Programs to Deter Undiagnosed African-American Youth from Juvenile Detention*, 11 S.J. POL’Y & JUST. 140, 147 (2017).

148. *Id.* at 148 (noting that in some “[s]pecial circumstances such as possession of a weapon on school premises, possession or selling of illegal drugs on school premises, or serious bodily harm to another on school premises, can warrant the student’s removal to an interim alternative education setting for up to 45 days”).

a result of disability or the school's failure to meet the requirements of the IEP, the student cannot be suspended.¹⁴⁹ Moreover, "if a child in special education is suspended the school must still provide post-expulsion services that are more than minimal homebound services as determined by the IEP."¹⁵⁰ As a result, punishment for similar conduct by similarly situated children could be dependent upon a diagnosis.

Despite these many challenges, there are a range of prospective policy and litigation solutions that can be implemented as short-and long-term strategies to resolve these gaps. For instance, universal access to pre-kindergarten (Pre-K) could be a primary means of ensuring access to quality early education services for all children, as well as earlier intervention for children with developmental delays.¹⁵¹ The former Secretary of Education suggests that societal investments in early childhood education yield returns upwards of eight to one.¹⁵² Moreover, Pre-K is a means for reducing inequality by leveling the playing field for children from low-income families.¹⁵³

Various school discipline reform efforts continue to gain traction, as well. Although it is impossible to summarize all prospective school discipline reform solutions offered by educational professionals, scholars, and researchers, their efforts often focus on reducing the criminalization of misbehavior in the school setting, limiting time spent outside of the educational setting, or creating equity in disciplinary enforcement.¹⁵⁴

149. *Id.* at 147.

150. *Id.* at 148.

151. See Brian McWalters, *The Federal Role in Universal Pre-K*, 2019 B.Y.U. EDUC. & L. J. 21, 26 (2019) (explaining that the term universal Pre-K indicates a system in which all children, regardless of socio-economic status, are afforded the opportunity to attend free preschool, in contrast to targeted Pre-K, in which education services are made available specifically for low-income children and noting that there are potential benefits to a universal, as opposed to targeted, approach).

152. *Press Briefing*, Press Secretary Josh Earnest & Secretary of Education John King Jr. (2016), 2016 WL 5540012, at *3.

153. OFF. OF THE PRESS SECRETARY, *Fact Sheet President Obama's Plan for Early Education for All Americans*, Obama White House (Feb. 13, 2013), obamawhitehouse.archives.gov/the-press-office/2013/02/13/fact-sheet-president-obama-s-plan-early-education-all-americans.

154. See, e.g., Matthew P. Steinberg & Johanna Lacoë, *What Do We Know About School Discipline Reform?*, EDUC. NEXT (2017), www.educationnext.org/what-do-we-know-about-school-discipline-reform-suspensions-expulsions/ (reporting strategies that use "nonpunitive approaches to address misbehavior," advocating for "alterative disciplinary strategies that allow students to stay in school and not miss valuable learning time," and warning how some policies had "disproportionate and unjustified effect on students of a particular race").

Disparate impact liability litigation is one such prospective solution and has been considered important in challenging policies or practices based on their adverse consequences, regardless of the underlying motivations.¹⁵⁵ The power of this theory was highlighted by an example provided in the 2014 Dear Colleague Letter, where Asian-American students were disparately impacted by a zero tolerance tardiness policy. Although the school's strategy was to further the legitimate, nondiscriminatory goal of promoting attendance, the policy has an impermissibly disproportionate impact on Asian-American students, who in the illustration tended to live farther from school and were more likely to rely on undependable public transit.¹⁵⁶ Applying this lens to the disproportionality of school punishment would be equally as important.¹⁵⁷ Other suggested reforms focus on the school level, such as the replacement of SROs with services¹⁵⁸ or access to counsel at critical stages of the disciplinary process,¹⁵⁹ among others. Other reforms still focus on systemic issues, such as teacher training and qualifications, as part of the solution.¹⁶⁰

155. Johanna Miller, *Protecting Children's Rights in School Discipline*, 34 No. 2 GPSOLO 28, 30–31 (2017) (finding that “[s]tatistics from the U.S. Department of Education show that suspensions are enforced at disproportionately high rates against students of color and students with disabilities” and noting “[t]here are many reasons to be concerned about this disproportionality: It contributes to the ‘achievement gap,’ it impacts graduation rates, and, as disparate treatment under the law, it may be a violation of students’ civil rights.”).

156. See PRESS OFF., U.S. DEP’T OF EDUC., U.S. Departments of Education and Justice Release School Discipline Guidance Package to Enhance School Climate and Improve School Discipline Policies/Practices (Jan. 8, 2014), www.ed.gov/news/press-releases/us-departments-education-and-justice-release-school-discipline-guidance-package; Joint Dear Colleague Letter from the U.S. Department of Justice, Civil Rights Division & U.S. Department of Education, OFF. FOR CIV. RTS., DEP’T OF EDUC. (Jan. 8, 2014), www2.ed.gov/about/offices/list/ocr/letters/colleague-201401-title-vi.html.

157. See NORA GORDON, *DISPROPORTIONALITY IN STUDENT DISCIPLINE: CONNECTING POLICY TO RESEARCH* (BROOKINGS INST. 2018), www.brookings.edu/research/disproportionality-in-student-discipline-connecting-policy-to-research/; see also Carone, *supra* note 138, at 147.

158. DIGNITY IN SCHS., *MODEL POLICIES TO FIGHT CRIMINALIZATION: A COLLECTION OF UPDATED RESOURCES FROM OUR MODEL CODE ON EDUCATION & DIGNITY*, 15 (2018).

159. Julie K. Waterstone, *Counsel in School Exclusion Cases: Leveling the Playing Field*, 46 SETON HALL L. REV. 471, 473 (2016).

160. See, e.g., Suevon Lee, *Hawaii Board of Education Votes To Approve Extra Pay For Hard-To-Find Teachers*, HONOLULU CIV. BEAT (Dec. 5, 2019), www.civilbeat.org/2019/12/hawaii-board-of-education-votes-to-approve-extra-pay-for-hard-to-find-teachers/ (discussing Hawaii Board of Education approving an

Additionally, there must also be remedies for the shortcomings within the referral, testing, and service-delivery process for special education. Despite strong mandates for quality educational services, often there are insufficient resources to fully effectuate the standard conceptualized within the law, especially for low socioeconomic status (low-SES) students of color.¹⁶¹ Here, too, a range of solutions have been proposed. These range from ensuring easy access to care for those who may need it,¹⁶² to modifying the mechanisms of our special education process,¹⁶³ among others.¹⁶⁴

To be clear, these reform efforts should not just be conceptualized on a federal level. Rather, because states and localities have historically played a leading role in education, reform efforts may best be accomplished through state or local actors.¹⁶⁵ Local managing entities, such as school boards or school committees, that are located in the communities served by the schools can have a profound impact in creating change that is responsive to local need. This is also a strategy that could prove useful on the litigation front, as various state constitutions or statutes may provide more expansive and robust protections, and the foundation of a lawsuit. For instance, the Florida Constitution has a nondiscrimination provision that prohibits any person

increase in pay for teachers who specialize in areas such as special education and Hawaiian language immersion).

161. Shameka Stanford & Bahiyyah Muhammad, *The Confluence of Language and Learning Disorders and the School-to-Prison Pipeline Among Minority Students of Color: A Critical Race Theory*, 26 AM. U. J. GENDER SOC. POL'Y & L. 691, 712 (2018).

162. Kristin Stanberry, *Finding Out If Your Child Is Eligible for Special Education*, UNDERSTOOD.ORG, www.understood.org/en/school-learning/special-services/special-education-basics/finding-out-if-your-child-is-eligible-for-special-education?_ul=1*xln673*domain_userid*YW1wLVFRejByZVNpMFhvVkJGUXBkR3Y4c2c (last visited Apr. 5, 2020) (explaining that, “even if your child has a ‘covered’ disability, she still might not be eligible” for special education services because the child’s “school may determine that the disability doesn’t keep her from learning adequately in the general education classroom”).

163. Tracy Thompson, *The Special-Education Charade: Individualized Education Programs, or IEPs, Are One of the Greatest Pitfalls of the Country’s School System*, ATLANTIC (Jan. 3, 2016), www.theatlantic.com/education/archive/2016/01/the-charade-of-special-education-programs/421578/.

164. Nate Levenson, *Special Education Reform Is Entering a New Era*, EDUC. WEEK (Feb. 11, 2019, 9:00 AM), blogs.edweek.org/edweek/rick_hess_straight_up/2019/02/special_education_reform_is_entering_a_new_era.html.

165. Jennifer Safstrom, *States as Civil Rights Actors: Assessing Advocacy Mechanisms within a State’s Legislative, Executive, and Judicial Branches*, 24 BARRY L. REV. 53, 54 (2019).

from “be[ing] deprived of any right because of race, religion, national origin, or *physical disability*.”¹⁶⁶ Although not without limits, this provision protecting those with physical disabilities may provide the basis for future legal challenge to access supports or accommodations, or to dispute a policy. This may be a helpful avenue for progress in a state that has otherwise failed to find constitutional deficiency with the educational system.¹⁶⁷ Other states should seek to assess what novel grounds might exist for challenging inequitable practices within their respective frameworks, including state constitution educational provisions; looking at state constitutional and legislative pathways, beyond the scope of federal protections in the IDEA, ADA, and related national laws, may prove to have the greatest traction.

Although far from comprehensive, these are just some of the leading solutions that could be used to mitigate the adverse educational consequences resulting from developmental delays, as well as the resulting lack of diagnosis and services. In order to minimize the detriment these delays can have in the long-term, prioritizing early intervention services, comprehensive reform, and innovative solutions, will help ensure the most optimal educational outcomes for children.

CRIMINAL LEGAL CONSEQUENCES

The devastating impacts of delaying or not providing interventions persist beyond the school context. Although the criminalization of school misconduct contributes to the school to prison pipeline, it is also significant to recognize that those with developmental delays are more likely to have interactions with the criminal legal system, either as juveniles or adults.¹⁶⁸

Unsurprisingly, individuals with disabilities are disproportionately affected in the criminal legal system.¹⁶⁹ Per one study, although less than 10

166. FLA. CONST. Art. II, § 2 (emphasis added).

167. Diane Rado, *FL Supreme Court Ends Longstanding Education Lawsuit, Ruling Against Advocates Fighting for Better Schools*, FLA. PHOENIX (Jan. 4, 2019), www.floridaphoenix.com/blog/florida-supreme-court-ends-longstanding-education-lawsuit-ruling-against-advocacy-groups-fighting-for-better-schools/.

168. WHEN INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES BECOME INVOLVED IN THE CRIMINAL JUSTICE SYSTEM: A GUIDE FOR ATTORNEYS, ARC OF N. VA. & ARC OF LOUDOUN 6 (2018).

169. David E. Houchins et al., *Barriers and Facilitators to Providing Incarcerated Youth With a Quality Education*, 53 PREVENTING SCH. FAILURE: ALT. EDUC. FOR CHILDREN AND YOUTH 159, 165 (2009); PETER E. LEONE ET AL., SCHOOL FAILURE, RACE, AND DISABILITY: PROMOTING POSITIVE OUTCOMES, DECREASING VULNERABILITY FOR INVOLVEMENT WITH THE JUVENILE DELINQUENCY SYSTEM, NAT’L CTR. ON EDUC., DISABILITY, & JUVENILE JUST. 3 (2003); Lawrence Ingalls, et al., *An Evaluation of Past Special Education*

percent of public school students are identified as having a disability, children with a diagnosed disability “make up 32 percent of youth in juvenile detention centers.”¹⁷⁰ However, as the Department of Education has acknowledged, estimates “of incarcerated youth with disabilities typically range from 30 percent to 60 percent, with some estimates as high as 85 percent.”¹⁷¹ Nationally, about 54,000 youth reside in a juvenile correctional facility at any given time.¹⁷² Upon entering the criminal legal system, students with or without a diagnosis lose prospective protections.¹⁷³ For instance, the IDEA “allows states to refuse to provide a free, appropriate education to incarcerated individuals aged eighteen to twenty-one who would otherwise be eligible if, by age eighteen, they have not been identified as disabled under the statute.”¹⁷⁴ It also exempts states of their obligation to provide transition services or to even test juveniles who are sentenced and placed in adult facilities.¹⁷⁵

This is because individuals with a disability are overrepresented at every stage of interacting with law enforcement. Individuals with a disability are arrested more frequently and are often in conditions more likely to result in interactions with law enforcement.¹⁷⁶ They are also over two-thirds more likely to be arrested for low-level crimes if displaying symptoms of mental disability than if not.¹⁷⁷ Individuals with a disability received higher

Programs and Services Provided to Incarcerated Young Offenders, 16 J. OF AT-RISK ISSUES 25, 27 (2011).

170. Carone, *supra* note 138, at 140.

171. *Supporting Youth with Disabilities in Juvenile Corrections*, U.S. DEP’T OF EDUC.: OFF. SPECIAL EDUC. & REHABILITATIVE SERVS. (May 23, 2017), sites.ed.gov/osers/2017/05/supporting-youth-with-disabilities-in-juvenile-corrections/.

172. *Id.*

173. Simoneau, *supra* note 130, at 90.

174. *Id.*

175. *Id.*

176. MENTALLY ILL OFFENDERS IN THE CRIMINAL JUSTICE SYSTEM: AN ANALYSIS & PRESCRIPTION, SENTENCING PROJECT 7 (2002), www.sentencingproject.org/doc/publications/sl_mentallyilloffenders.pdf (citing the Bureau of Justice Statistics, “prisoners with mental illness were twice as likely as other inmates to have been homeless prior to their arrest; forty percent were unemployed; and nearly half said they were binge drinkers”).

177. Linda Teplin, *Criminalizing Mental Disorder: The Comparative Arrest Rate Of The Mentally Ill*, 39 AM. PSYCHOLOGIST 794, 799 (Jul. 1, 1984); *see also* ROBERT BERNSTEIN & TAMMY SELTZER, *THE ROLE OF MENTAL HEALTH COURTS IN THE CRIMINAL JUSTICE SYSTEM* 2 (BAZELON CTR., 2003) (stating that a study of Chicago police found encounters that arrest rates for people with mental illness were almost twice as high as arrest rates for those without for the same offenses: 47 percent vs. 28 percent, respectively).

sentences, with stays in jails that are up to eight times longer than those without mental disabilities.¹⁷⁸ They are also more likely to be denied for parole or early release.¹⁷⁹ Finally, people with disabilities return to prison more frequently and more quickly than those without a disability.¹⁸⁰

Yet, there is a range of solutions available here, too, to address the challenges that a lack of early identification and treatment can have over an individual's life course. There are a host of proposed reforms—ranging from sentencing reform¹⁸¹ to legalization and expungement efforts¹⁸²—that would undoubtedly have positive effects for many currently incarcerated individuals, including those with developmental delays. There are also broad efforts to ensure full inclusion for those individuals seeking to exercise their

178. Michael Ollove, *Getting the Mentally Ill Out of Jails*, STATELINE (Apr. 7, 2017), www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2017/04/07/getting-the-mentally-ill-out-of-jails.

179. See COUNCIL OF STATE GOV'TS, CRIMINAL JUSTICE/MENTAL HEALTH CONSENSUS PROJECT 9 (2013) (discussing that the average stay at Riker's Island Jail is 42 days compared to 215 days for inmates with mental illness); see also PAULA M. DITTON, BUREAU OF JUSTICE STATISTICS, SPECIAL REPORT: MENTAL HEALTH AND TREATMENT OF INMATES AND PROBATIONERS 8 (1999) (showing inmates with disabilities are sentenced to an average of 15 more months in prison compared to other inmates with similar convictions); see also STANFORD JUSTICE ADVOCACY PROJECT, CONFRONTING CALIFORNIA'S CONTINUING PRISON CRISIS: PREVALENCE AND SEVERITY OF MENTAL ILLNESS AMONG CALIFORNIA PRISONERS ON THE RISE 2 (2017) (explaining that, "[o]n average, prisoners with mental illness in California receive sentences that are 12 percent longer than prisoners convicted of the same crimes but without mental health diagnoses"); see also Verified Complaint at 4, *Prisoner A v. State of Vermont et al.*, No. 2:15-CV-00221 (dismissed Oct. 15, 2012) (stating "Plaintiffs minimum sentence was served on July 13, 2013, but he continues to be held at Southern State Correctional Facility because of the failure of Defendants to have a reasonably functional system in place to identify and implement appropriate disability-related supports in the community to prevent continued, unnecessary and harmful institutionalization").

180. Jacques Baillargeon, et al., *Parole Revocation Among Prison Inmates with Psychiatric and Substance Use Disorders*, 60 PSYCHIATRIC SERVS. 1516, 1519 (2009); Jacques Baillargeon et al., *Psychiatric Disorders and Repeat Incarcerations: The Revolving Prison Door*, 166 AM. J. PSYCHIATRY 103, 105 (2009).

181. German Lopez, *The First Step Act, Congress's Criminal Justice Reform Bill, Explained*, VOX (Dec. 11, 2018), www.vox.com/future-perfect/2018/12/3/18122392/first-step-act-criminal-justice-reform-bill-congress.

182. Robert McCoppin, *Getting Marijuana Convictions Expunged in Illinois: What You Need to Know About the Process*, CHI. TRIBUNE (Aug. 30, 2019), www.chicagotribune.com/marijuana/illinois/ct-cb-weed-conviction-expunged-illinois-20190917-o2jrwf43trefbnb54efohdmwzu-story.html.

rights post-incarceration.¹⁸³ However, there are also targeted efforts that could have a unique impact on persons with special needs.

For instance, the use of crisis intervention teams (CIT) or other specialized response units aim to help meet the unique needs of those who are in crisis.¹⁸⁴ This is significant because it is estimated that at least half of the people shot and killed each year by police are people with disabilities.¹⁸⁵ Although many of these individuals may be suffering from a mental health crisis, individuals with autism, deafness, or a disability that may be mistaken for intoxication such as diabetes or epilepsy, are also at an increased risk.¹⁸⁶

There is also the need for treatment and diversionary programs to better respond to an individual's mental health, substance abuse, or other needs outside of a jail or prison setting. At least one estimate has suggested that nearly 65 percent of local jail populations are demonstrating some type of mental disability or illness.¹⁸⁷ Yet it is possible for intervention programming to reduce rates of recidivism, and accordingly, reduce the jail population.¹⁸⁸ This would not only provide more appropriate treatment for those in need of services, but would lead to significant savings.¹⁸⁹ Additionally, front-end evaluations as individuals come into contact with the criminal legal system would also provide information relevant to treatment and care. Although diversion should be the primary goal, increased health access, mental health

183. Matt Vasilogambros, *Voting Rights Restoration Gives Felons a Voice in More States*, FLA. PHOENIX (Jan. 6, 2020), www.floridaphoenix.com/2020/01/06/voting-rights-restoration-gives-felons-a-voice-in-more-states/.

184. David M. Perry & Lawrence Carter-Long, *How Misunderstanding Disability Leads to Police Violence*, ATLANTIC (May 6, 2014), timeli.info/item/1601815/The_Atlantic_Health/How_Misunderstanding_Disability_Leads_to_Police_Violence.

185. *Deadly Force: Police & The Mentally Ill*, PORTLAND PRESS HERALD (2012), www.pressherald.com/interactive/maine_police_deadly_force_series_day_1/.

186. Perry & Carter-Long, *supra* note 184.

187. *Study Finds More Than Half of All Prison and Jail Inmates Have Mental Health Problems*, BUREAU OF JUST. STATISTICS (Sept. 6, 2006), www.bjs.gov/content/pub/press/mhppjipr.cfm.

188. Marissa Gerber, *Mental Illness Program Could Transform LA County Justice System*, L.A. TIMES (Sept. 17, 2014), www.latimes.com/local/countygovernment/la-me-mental-health-courts-20140918-story.html (reporting that a Florida program started in 2000 to divert low-level misdemeanor offenders with psychiatric disabilities reduced recidivism rates from 72% to 20%, cut the local jail population nearly in half, and allowed the county to close a jail.)

189. COUNCIL OF ECON. ADVISERS, RETURNS OF INVESTMENTS IN RECIDIVISM-REDUCING PROGRAMS 1 (2018).

services, and other forms of treatment should be provided as needed even within the jail or prison context. The connection between mental health and criminal legal system reforms should serve as a foundation for future reform efforts.¹⁹⁰

In addition, legal professionals also play an important role in ensuring that individuals who interact with the criminal legal system are protected. Attorneys should increase their health and developmental fluency so as to be aware of and more easily identify prospective signs of developmental delay or mental illness that would indicate need for evaluation or treatment.¹⁹¹ While advocates seek to reform diminished capacity defenses, they should also utilize them as appropriate, including affirmatively requesting testing.¹⁹² Legal advocates should also insist upon parity between resources allotted to the prosecution and defense in order to avoid distortions in the adversarial system.¹⁹³ Moreover, enhancing medical-legal partnerships can best leverage both medical and legal services to advance health and wellness.¹⁹⁴

Although there are many other reforms that would have large-scale benefits, these are among some of the most important changes to significantly assist those with developmental disabilities. Especially in the criminal legal context, it is important to recognize that “people of color with disabilities face myriad and complex forms of intersectional discrimination that are distinct from the discrimination experienced by either people of color or people with disabilities generally.”¹⁹⁵ Continuing to collect data and dedicating research efforts to understanding this issue can help illuminate next steps to adequately remedy the intersectional discrimination faced by differently abled individuals within the criminal legal system.

190. John Hanna, *AG: Mental Health Treatment Funding Key to Kan. Criminal Justice Reform*, HAYSPPOST & EAGLE RADIO (Jan 1, 2020, 2:59 PM), hayspost.com/posts/5e0d082b57544d3fe90e8a19.

191. See Marie Albiges, *Virginia Wants to Help People with Mental Illness Navigate the Criminal Justice System*, DAILY PRESS (Nov. 9, 2018), www.dailypress.com/virginia/dp-nw-mental-health-jails-initiative-20181109-story.html (recounting an instance of an attorney recognizing the defendant suffered from a mental illness).

192. VA. DEP'T OF BEHAVIORAL HEALTH & DEVELOPMENTAL SERVS., SECTION 1: THE INSANITY DEFENSE & THE NGRI FINDING 3, 10 (2016).

193. Ned Oliver, *Most Public Defenders in Richmond Make Less Than a Secretary in the Prosecutor's Office. They Want a Raise*, VA. MERCURY (Sept. 30, 2019), www.virginiamercury.com/2019/09/30/most-public-defenders-in-richmond-make-less-than-a-secretary-in-the-prosecutors-office-they-want-a-raise/.

194. *The Need*, MILKEN INST. SCH. OF PUB. HEALTH, medical-legalpartnership.org/need (last visited Apr. 5, 2020).

195. Abrokwa, *supra* note 134, at 47.

CONCLUSION

There are countless health, educational, and legal consequences associated with an individual's access to, utilization of, and level of quality received in terms of health care. The results of delayed or inexistent interventions can have devastating and long-lasting negative impacts on the lives of many. By placing an emphasis on early diagnosis, intervention, and treatment for a child, there is a significant reduction in the likelihood of experiencing difficulties in an academic setting or becoming involved in the juvenile justice system.