

University of Maryland Francis King Carey School of Law

DigitalCommons@UM Carey Law

Faculty Scholarship

Francis King Carey School of Law Faculty

2014

Special Kids, Special Parents, Special Education

Karen Syma Czapanskiy

University of Maryland Francis King Carey School of Law, kczapanskiy@law.umaryland.edu

Follow this and additional works at: https://digitalcommons.law.umaryland.edu/fac_pubs



Part of the [Education Law Commons](#)

Digital Commons Citation

47 Michigan Journal of Law Reform 733 (2014).

This Article is brought to you for free and open access by the Francis King Carey School of Law Faculty at DigitalCommons@UM Carey Law. It has been accepted for inclusion in Faculty Scholarship by an authorized administrator of DigitalCommons@UM Carey Law. For more information, please contact smccarty@law.umaryland.edu.

SPECIAL KIDS, SPECIAL PARENTS, SPECIAL EDUCATION

Karen Syma Czapanskiy*

Many parents are raising children whose mental, physical, cognitive, emotional, or developmental issues diminish their capacity to be educated in the same ways as other children. Over six million of these children receive special education services under mandates of the Individuals with Disabilities Education Act, called the IDEA. Once largely excluded from public education, these children are now entitled to a “free appropriate public education,” or FAPE. This Article argues that the promise of the IDEA cannot be realized unless more attention is paid to the child’s parents. Under the IDEA, as in life, the intermediary between the child and the educational system is the child’s parent. The law appears to empower parents to participate in the planning, execution, and revision of the child’s individual educational plan. The experience of parents, however, is often not empowering, to the detriment of both child and parent. Instead, many parents confront school systems that fail to support parental competence or help parents conserve their resources.

This Article proposes three significant reforms to the special education system that better serve the needs of parents while improving the chances that children in need of special education will receive it. The three reforms are: (1) requiring schools to help parents be in touch with each other; (2) requiring school systems to commit to common special educational plans through a public process; and (3) adopting universal design pedagogies in general education when practicable. Although the most expensive of the three proposals is the preference for universal design pedagogies, the most controversial is requiring school systems to commit to common special educational plans for similarly-situated children. If the proposal were adopted, every child with the same problem would be provided with the same educational plan. The individualized plan now mandated would be provided only where a child’s situation is an uncommon one.

None of the proposed reforms is cost-free. I conclude by demonstrating that the costs of parent-oriented reforms are justified in order to comply with congressional expectations, for reasons of pragmatism, and to advance social justice for parents with special needs children as compared with other parents and with each other.

* Francis & Harriet Iglehart Research Professor of Law, University of Maryland Francis King Carey School of Law. Thanks are due to many people who helped me develop, articulate, and support the ideas in this Article. They include participants at the Regional ISFL Meeting at the University of Iowa School of Law and the University of Cincinnati Conference on Social Justice Feminism, Dana Czapanskiy, Margaret Meissner, and Professors Laura Rothstein and Theresa Glennon. Special thanks go to research assistants Garland Rowland, Lauren West, Cynthia Polasko, and Shun-yiu (Leon) Wong. My research has been generously supported by the University of Maryland Francis King Carey School of Law.

INTRODUCTION

Many parents are raising children whose mental, physical, cognitive, emotional, or developmental issues diminish their capacity to be educated in the same ways as other children. Over six million of these children receive special education services under mandates of the Individuals with Disabilities Education Act (IDEA).¹ Once largely excluded from public education,² these children are now entitled to a “free appropriate public education.”³ Whether a child gets the full benefit of the promised education turns on many factors. This Article argues that a key factor is the child’s parents. More specifically, it argues that special education systems can and should be redesigned to support parental competence and conserve parental resources. If reforms of the types suggested here were implemented, children in need of special education would be more likely to receive it.

Unlike parents of children in general education classrooms, parents of children in need of special education are expected to be heavily involved in their child’s education. They are given roles to play in establishing the child’s eligibility for special education, identifying what the child’s educational plan should contain, and monitoring whether the plan is being put into effect. Effective parents often invest substantial time in monitoring their child’s education and develop expertise about the educational needs of the child and the services available to meet those needs. Parents are called on to advocate and negotiate for their child in situations where everyone else in the room is a professional in education and child development and where many of those same professionals will be part of the child’s daily life that year and for several years to

1. 20 U.S.C. §§ 1400–1474 (2006); see Eloise Pasachoff, *Special Education, Poverty, and the Limits of Private Enforcement*, 86 NOTRE DAME L. REV. 1413, 1421 (2011).

2. See H.R. REP. NO. 94-332, at 11–12 (1975) (finding that 1.75 million children of school age were entirely excluded from the public schools and another 2.5 million were in programs that failed to satisfy their educational needs); David Neal & David L. Kirp, *The Allure of Legalization Reconsidered: The Case of Special Education*, 48 L. & CONTEMP. PROBS. 63, 67 (1985) (noting two million handicapped children were excluded from school in 1970); David Kirp, William Buss & Peter Kuriloff, *Legal Reform of Special Education: Empirical Studies and Procedural Proposals*, 62 CAL. L. REV. 40, 41 (1974); H. Rutherford Turnbull, III, Karrie A. Shogren & Ann P. Turnbull, *Evolution of the Parent Movement*, in HANDBOOK OF SPECIAL EDUCATION (James M. Kauffman & Daniel P. Hallahan eds., 2011) (reviewing parental involvement in development of special education).

3. See 20 U.S.C. § 1401(9) (2006) (defining “free appropriate public education”); 20 U.S.C. § 1412(a)(1) (2006) (stating requirement that states provide free appropriate education as condition for receiving certain federal funds); LAURA ROTHSTEIN & JULIA IRZYK, *DISABILITIES AND THE LAW* §§ 2:7, 2:19–2:21 (4th ed. 2012).

come.⁴ At the same time, a parent may be managing a child's complex home-based medical regime and coordinating other therapeutic interventions from multiple providers. All of these challenges confront parents who may also experience unusually large medical costs for the child, unusually low incomes because of time and energy spent meeting the child's needs, and unusually high degrees of social and emotional isolation because of their relationship with the child.⁵

Special education practices can and should be changed to be more parent-friendly or parent-oriented, particularly in terms of supporting parental competence and conserving parental resources. Part I describes the experiences of two families with children in need of special education. One family happens to live in a place where educators have adopted parent-oriented practices, while the other family lives in a place with a more common set of special education practices. As explained in Part II, it is likely that neither family has a complaint under current law. Part III categorizes parent-friendly practices as those which support and respect parental competence and those which help parents conserve resources of time and money. Part IV illustrates how the goal of making special education practices more parent-oriented can be advanced in three ways: putting parents in touch with each other, requiring school systems to commit to common special educational plans through a public process, and adopting universal design practices in general education when practicable. The costs of

4. See David M. Engel, *Law, Culture, and Children with Disabilities: Educational Rights and the Construction of Difference*, 1991 DUKE L.J. 166, 188–89 (observing that parents describe themselves in IEP meetings as “terrified and inarticulate”; they do not see their understanding of the child as being credited by the decisionmakers); Theresa Glennon, *Disabling Ambiguities: Confronting Barriers to the Education of Students with Emotional Disabilities*, 60 TENN. L. REV. 295, 352 (1993); Neal & Kirp, *supra* note 2, at 78 (stating that due process hearings are most likely to be used by higher-income parents in part because their resources give them option to avoid continuing conflict with school by removing child to different educational situation); COLIN ONG-DEAN, *DISTINGUISHING DISABILITY: PARENTS, PRIVILEGE, AND SPECIAL EDUCATION* 113–60 (2009) (noting that few parents seek hearings and even fewer prevail; pursuing relief requires investment of resources that few parents possess; possibility of gain relative to loss important to parental decision, so parents more likely to seek hearing for reimbursement).

5. See Susan L. Neely-Barnes, David A. Dia, *Families of Children with Disabilities: A Review of Literature and Recommendations for Interventions*, 5 J. EARLY & INTENSIVE BEHAV. INTERVENTION 93 (2008) (reviewing the complex lives of parents of children with disabilities); Karen Syma Czapanskiy, *Disabled Kids and Their Moms: Caregivers and Horizontal Equity*, 19 GEO. J. POVERTY L. & POL'Y 43, 55–57 (2012) (documenting experience of parents of child with special needs and economic consequences to parents); Karen Syma Czapanskiy, *Chalimony: Seeking Equity Between Parents of Children with Disabilities and Chronic Illnesses*, 34 N.Y.U. REV. L. & SOC. CHANGE 253, 264–70 (2010) (documenting economic and social consequences of raising a child with special health care needs).

parent-oriented reforms can be justified in at least four ways, as demonstrated in Part V. First, Congress intended parents to be involved in the special education process, so making the system more parent-oriented advances the congressional objective. The second is pragmatic, since parents who bring more competence and greater resources to childrearing may improve their children's chances for success. Third, the reforms will improve social justice for parents with special needs children as compared with other parents. Finally, the changes will help to ensure equality among special needs parents.

I. CHARLIE, SUSIE, AND THEIR PARENTS

The stories of Charlie and Susie, detailed below, illuminate some of the challenges faced by parents raising children eligible for special education.⁶ Both Charlie and Susie are diagnosed early in life with autism, a developmental disorder characterized by impairments in social interactions and communication skills, as well as “restricted, repetitive patterns of behavior, interests or activities.”⁷ School systems around the country are responding to recent increases in the numbers of children on the autism spectrum. Approximately eleven out of every 1,000 eight year olds in the United States were found to be on the autism spectrum in 2008,⁸ and schools experienced an increase of over 500 percent in the numbers of students on the spectrum receiving services under the

6. The stories of Charlie and Susie are not about individual children. Instead, they are based on many experiences and a wide variety of sources. Over the years, I have represented clients whose families included special needs children and engaged in multiple conversations with friends, neighbors, and colleagues about their families. My spouse, Dana Czapanskiy, spent numerous years counseling families with special needs children. Without revealing confidential information about his clients, Dana has expanded and deepened my understanding of the kinds of challenges many of the families face. My understanding has been enhanced by lurking on various listservs, such as the one described in Section IV(A), as well as by reading research by scholars and accounts by parents and journalists. Many of those are cited throughout this Article.

7. AMERICAN PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL-V § 299.00 (5th ed. 2000); see TEMPLE GRANDIN & CATHERINE JOHNSON, ANIMALS IN TRANSLATION: USING THE MYSTERIES OF AUTISM TO DECODE ANIMAL BEHAVIOR (2005) (discussing the way an animal scientist connects her autism with her special interest in and capacity to understand animals); RUPERT ISAACSON, THE HORSE BOY: A FATHER'S QUEST TO HEAL HIS SON (2009) (describing an account by father of autistic boy about the child's unusual responsiveness to horses).

8. CTR. FOR DISEASE CONTROL & PREVENTION, *Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008*, 61 MORBIDITY & MORTALITY WKLY REP. SURVEILLANCE SUMMARIES 1–19 (Mar.30, 2012), http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w.

IDEA between 1993 and 2002.⁹ Services for this population are among the most expensive provided under the IDEA, so the increasing number of affected children threatens the budgets of both parents and schools.¹⁰

From the start, Charlie experiences an education system that pays attention to him as a member of a family, and his parents are included in every way. Susie, on the other hand, experiences her early education in a system that addresses her needs separately from those of her parents, who are largely ignored. Susie's parents struggle more than Charlie's to develop the competencies they need to help their daughter while conserving their resources. The stories of these two children and their parents are given in some detail to afford the reader a deeper appreciation for their experiences in and out of the educational setting. Although the stories are as thorough as possible in the context of a single article, they still omit some features common to many of these families, such as the presence of siblings, single-parenting, and deep poverty.

A. *Charlie*

Not long after Charlie turned one, his parents, Eleanor and Martin, began to worry about his development.¹¹ Unlike the other children, he never hugged or smiled at daycare center staff. None of his utterances resembled English.¹² Occasionally, he would

9. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-05-220, SPECIAL EDUCATION: CHILDREN WITH AUTISM (2005), available at <http://www.gao.gov/new.items/d05220.pdf> (reporting that more than 120,000 children on autism spectrum receiving services under IDEA in 2002; number increased more than 500 percent between 1993 and 2002; average per pupil expenditure for children with autism in 1999–2000 exceeded 18,000 dollars); NAT'L CTR. FOR EDUC. STATISTICS, CHILDREN 3 TO 21 YEARS OLD SERVED UNDER INDIVIDUALS WITH DISABILITIES EDUCATION ACT, PART B, BY TYPE OF DISABILITY: SELECTED YEARS, 1976–77 THROUGH 2009–10 (Sept. 2011), available at http://nces.ed.gov/programs/digest/d11/tables/dt11_046.asp (stating that 378,000 students with autism served under IDEA in 2009–2010).

10. Mark C. Weber, *Reflections on the New Individuals with Disabilities Education Improvement Act*, 58 FLA. L. REV. 7, 46 (2006) (stating that the average cost of therapies for child on autism spectrum is 33,000 dollars per year); Terry Jean Seligmann, *Rowley Comes Home to Roost: Judicial Review of Autism Special Education Disputes*, 9 U.C. DAVIS J. JUV. L. & POL'Y 217, 285–86 (2005) (noting that the extremely high cost of services for children on autism spectrum is the “elephant in the room,” explaining degree of resistance of school systems to agreeing to common therapy plans).

11. See Fred Volkmar, Kasia Chawarska & Ami Klin, *Autism in Infancy and Early Childhood*, 56 ANNU. REV. PSYCHOL. 315, 317 (2005) (stating that ninety percent of parents of children on the spectrum identified problems in their child's development before the child turned two).

12. See *id.* at 318 (noting that it is common for young children on the spectrum to have limited language and social skills).

scream and rock back and forth for hours, and nothing could comfort him. When the family walked around the neighborhood, Charlie would get excited about the dogs and birds, but he never interacted with people. After an outburst during which he hit another child, a daycare teacher recommended an evaluation. Charlie was found to be on the autism spectrum, probably on the more extreme end.

Even before Charlie's diagnosis, Eleanor and Martin began to change their lifestyle. Because Charlie's outbursts and aggressive behaviors were more frequent when he was in an unfamiliar situation, they stayed close to home. They tried to avoid people who might misunderstand Charlie or criticize Eleanor and Martin for not controlling his loud or repetitive behaviors.¹³ As Eleanor described it, "I had been isolated to only playing with him at home. We couldn't even make it to the park to play. No one but family would interact with us." Charlie's disrupted sleep patterns kept his parents up all night, particularly since he was likely to run out of the house.

Charlie's pediatrician referred Eleanor and Martin to the local health department for "Child Find,"¹⁴ an early intervention program. Through a combination of home visits, consultations with the pediatrician, and an examination by a neuropsychologist (paid for by the department), the Child Find worker confirmed Charlie's diagnosis and began working with Eleanor and Martin to identify services. They agreed on a plan, called an Individualized Family Service Plan, or IFSP,¹⁵ to address Charlie's issues along with the difficulties that Eleanor and Martin were having as Charlie's parents.

13. See Rachel L. Swarns, *Testing Autism and Air Travel*, NY TIMES (Oct. 26, 2012), http://www.nytimes.com/2012/10/28/travel/testing-autism-and-air-travel.html?_r=0 (describing parents avoiding air travel because of unpredictability of child's response and critical reactions of other passengers and flight crew); Stuart A. Hindman, *The Air Carrier Access Act: It Is Time for an Overhaul*, 9 ISSUES AVIATION L. & POL'Y (2010).

14. "Child find" is the term used in IDEA to describe the obligation of states accepting federal funding under the Act to identify children in need of services. 20 U.S.C. § 1412(a)(3) (2006); 34 CFR § 300.111 (2012); see Laura C. Hoffman, *Ensuring Access to Health Care for the Autistic Child: More Is Needed than Federal Health Care Reform*, 41 SW. L. REV. 435, 463–65 (2012) (describing early intervention programs under Part C of the IDEA as they affect children on the autism spectrum, including the child find system); THE LEGAL CENT. FOR FOSTER CARE, EDUC., *Infants and Toddlers with Disabilities in the Child Welfare System: What Advocates Should Know About IDEA Part C*, 32 CHILD L. PRAC. 1, 5–6 (2013) (describing child find system as it applies to children in foster care, including early intervention services under Part C of IDEA).

15. See 20 U.S.C. § 1401(15) (2006) (defining "individualized family service plan"); *id.* § 1412(a)(4) (stating requirement that states provide IFSP as condition for receiving certain federal funds); *id.* § 1436 (2006) (stating requirements for IFSP).

Under the terms of the IFSP, Charlie spent forty hours a week at a small center in one of the county public school buildings. The center, created to respond to the increasing number of children on the autism spectrum, employed therapists and support workers. For up to thirty hours a week, children on the autism spectrum between the ages of two and six were offered Applied Behavior Analysis (ABA), a well-studied and highly effective therapeutic system.¹⁶ Staff also provided occupational and speech therapy. In an effort to help children on the spectrum learn how to interact with others, the center accepted a number of neuro-typical children into a daycare program. Parents were welcome to participate in therapeutic sessions whenever they could. The center also had staff and programs to help parents learn techniques for improving their children's behaviors, language, and social skills.

When Charlie turned three, the health department's role changed to one of transitioning Charlie to the school system. The name of the service plan changed from an IFSP to an Individual Education Plan (IEP), reflecting his transition from early intervention services to public education for older children.¹⁷ Despite the change in name, Charlie's daily program at the center did not change because the center was able to continue meeting Charlie's needs. Further, while Charlie's parents were not expressly mentioned in the IEP, the center's programs were open to all parents of children in the center, so they continued to get help. Finally, in addition to working with individual children and their parents, the center provided a hub for parents to meet each other, develop friendships, and share support. The county school system facilitated a listserv for parents of special needs children, so parents in and out of the center could keep in touch with each other even when their children moved on to other programs or places. They could also use the listserv to discuss what to expect when their children reached school age and to seek advice about how best to work with

16. Connie Anderson, *Behavior Therapies: Key Interventions in ASD*, INTERACTIVE AUTISM NETWORK, http://www.iancommunity.org/cs/simons_simplex_community/behavioral_therapies (June 6, 2012); see NAT'L AUTISM CTR., NATIONAL STANDARDS REPORT: ADDRESSING THE NEED FOR EVIDENCE-BASED PRACTICE GUIDELINES FOR AUTISM SPECTRUM DISORDERS (2009), available at http://www.nationalautismcenter.org/pdf/NAC%20NSP%20Report_FIN.pdf (effectiveness of behavioral therapy well established through research); Rachel Ratcliff Womack, *Autism and the Individuals with Disabilities Education Act: Are Autistic Children Receiving Appropriate Treatment in Our Schools?*, 34 TEX. TECH L. REV. 189 (2002) (describing ABA); Molly Helt et al., *Can Children with Autism Recover? If So, How?*, 18 NEUROPSYCHOLOGY REV. 339, 350 (2008) (describing behavioral treatment used in some or all cases where recovery from ASD occurred).

17. Compare 20 U.S.C. § 1414(d)(1)(a) (2006) (defining individualized education program) with 20 U.S.C. § 1436(a) (2006) (identifying elements of individualized family service plan).

the school system and others in the community, such as sports leagues, medical providers, and insurance companies.

By the time Charlie was old enough to enter kindergarten, he had begun to develop some expressive language and basic social skills. His aggressive and repetitive behaviors were less frequent. A team at the center provided a school-readiness report that reaffirmed Charlie's diagnosis on the autism spectrum, but his symptoms were identified as less severe than earlier in his life. The IEP team, consisting of Charlie's parents, a school representative, and an expert connected to the center, decided to have Charlie try five mornings a week in a kindergarten classroom located in the same building as the center, followed by afternoons in the center, where he would continue ABA and occupational and speech therapy. Center staff and teachers in the building knew each other and worked together whenever a child moved from the center into the school, so planning the transition was not difficult. Charlie's parents had no hesitation about signing the IEP. They were confident that Charlie's familiarity with the center would reduce his anxieties about change. They also appreciated the fact that Charlie could go to the center if he had a meltdown during the school day.

Over the course of Charlie's kindergarten year, under a program known as "response to intervention," or RTI, all kindergarten children were regularly tested to determine if they were making progress in the skills needed to begin reading and arithmetic.¹⁸ Charlie was tested along with the others, and interventions were designed for him and for other children who, from time to time, needed additional or specialized help to master the curriculum. Interventions were available to all children who needed them, regardless of whether the child was eligible for an IEP.

When Charlie's assessments demonstrated that his progress continued to be inadequate, the IEP team met again to decide how to respond. A paraprofessional was added to work with Charlie half an hour each morning on recognizing numbers and letters. Depending on Charlie's progress and the progress of other students, the paraprofessional sometimes worked individually with Charlie and sometimes worked in a small group that included Charlie. The paraprofessional sent a weekly email to Charlie's parents, teacher, and center therapists describing what Charlie was doing. They helped each other identify ways to supplement the effort at home, at school, and at the center. Retesting demonstrated enough progress for Charlie to advance to the first grade.

18. See *infra* notes 149–53 (describing the RTI program).

After Charlie had been at the center for several months, Eleanor and Martin began to feel more competent as parents. They felt less socially isolated and more capable of meeting their child's needs. With the help of other parents as well as center staff members, they felt more confident about asking for what they thought Charlie needed and explaining their reasoning. Gaining from the experiences of other parents, Eleanor and Martin identified some digestive problems that seemed to contribute to some of Charlie's outbursts. By changing his diet and getting him medical attention from a pediatric gastroenterologist, they helped him experience less pain and more enjoyment at mealtime. His sleep patterns were more regular, and his unpredictable outbursts were fewer when he spent time at the center. Family members and friends noticed the differences in Martin and Eleanor as well as in Charlie. Some began to ask if they could get together socially or even help out with Charlie on occasion.

While Charlie was in kindergarten, Martin became adept at getting him to practice his letters and numbers. Nonetheless, both he and Eleanor worried about Charlie losing his educational momentum during summer vacation. They decided to request that the IEP include year-round school.¹⁹ Through the center and the listserv, they shared their ideas with other parents and put together a group to meet with school board members.

B. *Susie*

In a neighboring county, Barbara and Harry's two-year-old daughter, Susie, was found to be on the more extreme end of the autism spectrum. Like Martin and Eleanor, Susie's parents learned about the possibility of an early intervention program from their pediatrician. Barbara and Harry's Child Find caseworker proposed an IFSP consisting of ten hours per week of ABA therapy in the family home at times when Susie and one of her parents could participate. Harry and Barbara agreed that Susie needed therapy, but they also felt that they were not doing well as parents for Susie. They asked for the plan to include training for them about how to communicate better with Susie, how to deal with her outbursts and repetitive behaviors, and how to help her speak with other people.

19. Parents often make such requests, but school boards resist them. See ROTHSTEIN & IRZYK, *supra* note 3, at § 2:20 & nn. 18–19; *Battle v. Pennsylvania*, 629 F.2d 269, 280 (3d Cir. 1980) (finding a violation of EAHC where IEP of more than 180 days a year of school was refused because of administrative policy and not because of individual consideration of unique needs of child).

The caseworker did not agree that education for Susie's parents could be included in the plan.

Once the ABA sessions began, Harry and Barbara found that the therapist was very helpful for Susie and that she could also teach them some ways to help Susie. The therapist recommended that they increase the hours of therapy each week so that Susie could make progress more rapidly. Barbara and Harry could rearrange their work schedules to be home for more hours, but they could not afford to pay for the therapy. They asked the caseworker for help, but she responded that ten hours was all she was able to authorize. She advised them that they had a right to demand a hearing if they wanted to have her decision reviewed.²⁰ Barbara was reluctant to alienate the caseworker, however, and neither she nor Harry thought that they had the time or energy to pursue a legal solution. So, they worked hard to make sure Susie got the most she could out of the ten hours of ABA therapy.

When Susie was almost three, it was time to evaluate her for preschool. The caseworker notified the local elementary school that Harry and Barbara would be seeking an IEP and offered to provide records and assist with the school's assessment of Susie. At the school, Harry and Barbara were told that they could apply to have Susie evaluated and that, if the evaluation showed a need for Susie to receive services, the school system would convene a meeting to discuss developing a plan. Given Susie's history with the Child Find program, it was not difficult to persuade the school system to have one of its staff psychologists evaluate her. After meeting with Susie and her parents and consulting with Susie's pediatrician, the ABA therapist, and the Child Find caseworker, the psychologist agreed that Susie needed special services if she were to benefit from education. The major problems were Susie's delays in language and social skills, her uncontrollable outbursts, and repetitive behaviors.

At the meeting about Susie's IEP, the school system proposed that Susie attend preschool three mornings a week for three hours each morning in a classroom with a teacher who was certified in special education. Each of the five other children in the class had exhibited some kind of behavioral issue or developmental delay. Susie would leave the classroom one hour each week for speech therapy and one hour each day for Pivotal Response Treatment (PRT), an established therapeutic approach for children on the autism spectrum.²¹ Barbara and Harry were welcome to join Susie for

20. See *infra* note 49 (identifying the statutory sources of right to due process).

21. See Connie Anderson, *Floortime and Pivotal Response Training*, INTERACTIVE AUTISM NETWORK, <http://www.autismspeaks.org/what-autism/treatment/pivotal-response-therapy>

the PRT therapy sessions if they thought it would be helpful to them.

Barbara and Harry were not satisfied. They wanted Susie to be in preschool for a full school day every day, not just nine hours per week. They wanted her to continue getting ABA therapy, and they wanted to be able to participate for more than one hour each day.²² In addition, they still wanted to become better parents to Susie, particularly in terms of her speech development, social skills, and repetitive behaviors. They were advised that they could seek a hearing, which they did. In the meantime, they did not sign the IEP, so Susie could not start school.

When Susie turned three, shortly before the school year began, her Child Find services ended. She stayed with a neighbor a few hours a day, so Barbara and Harry could go to work. Susie could not continue ABA therapy because it was too expensive. The impasse was not resolved for several months, despite efforts at mediation. After a hearing in front of an administrative judge, Barbara and Harry lost their appeal. Rather than go to court, they signed the IEP and Susie began preschool.

Two years later, Susie was old enough for kindergarten. During her preschool years, Susie's language had improved a bit, but her repetitive behaviors were still uncontrollable, and she could be explosive at times. Usually, she was able to play comfortably near the other children in her preschool classroom. She rarely interacted with people other than her parents, teachers, and favorite neighbor. At the annual IEP meeting, the school proposed that Susie attend the morning kindergarten at her neighborhood school. She would be taken out of the classroom one hour each day for PRT and speech therapy. If her behaviors disrupted the class, her parents would be called and one of them would have to come get her. The classroom teacher, while not certified in special education, had taught other children on the autism spectrum in prior years and thought she could help Susie learn. She invited Susie's parents to

prt (last visited Nov. 22, 2013); NAT'L AUTISM CTR., note 16, at 77–78 (finding that both behavioral therapy and pivotal response treatments are well established through research; question of what approach to use depends on factors such as professional judgment, experience, etc.).

22. See Amy Bitterman et al., *A National Sample of Preschoolers with Autism Spectrum Disorders: Special Education Services and Parent Satisfaction*, 38 J. AUTISM & DEVELOPMENTAL DISORDERS. 1509, 1515 (2008) (noting that parents of children with ASD are significantly more likely to want more hours of service than parents of children with other disabilities).

meet with her before school began to discuss any techniques they had learned to help Susie be comfortable in new environments.²³

As it turned out, Susie was away from her kindergarten classroom as much as she was in it. Her frequent outbursts distracted other children.²⁴ On average, her parents were called to pick her up two days each week. Barbara lost her job due to excessive absenteeism without prior authorization.²⁵ Susie achieved almost none of the learning goals met by other kindergarten students in her class.

At the annual IEP meeting to determine whether Susie should continue to have a plan for the coming year and, if so, what the plan should be, the school system recommended that she repeat kindergarten with all the same arrangements. Susie's parents refused to agree. They had no problem with her repeating kindergarten, but they wanted her enrolled for a full-day program that included tutoring, ABA therapy, and speech therapy. No agreement was reached, so Susie's parents demanded a hearing. In the meantime, Susie started the school year under the IEP from the

23. See NICHCY, AUTISM SPECTRUM DISORDERS (June 2010), available at <http://nichcy.org/wp-content/uploads/docs/fs1.pdf> (describing helpful approaches that general education teachers can use when a child on the autism spectrum is in the classroom).

24. See Megan Roberts, *The Individuals with Disabilities Education Act: Why Considering Individuals One at a Time Creates Untenable Situations for Students and Educators*, 55 UCLA L. REV. 1041 (2008) (giving examples of children whose conduct requires greater attention from the teacher and distracts teacher from attending to other children).

25. See Michael D. Kogan, Bonnie B. Strickland, Stephen J. Blumberg, Gopal K. Singh, James M. Perrin & Peter C. van Dyck, *Spectrum Disorder Among Children in the United States, 2005–2006: A National Profile of the Health Care Experiences and Family Impact of Autism*, 122 PEDIATRICS 1149, 1153 (2008) (“Parents of more than half of CSHCN [children with special health care needs] with ASD had to reduce or stop work to care for their child, and parents of >25% of CSHCN with ASD spend ≥10 hours weekly providing or coordinating their child’s care.”); Zuleyha Cidav, Steven C. Marcus & David S. Mandell, *Implications of Childhood Autism for Parental Employment and Earnings*, 129 PEDIATRICS 617, 617 (2012) (noting that children with ASD “are 9% less likely to have both parents working” than children with no health limitations, and mothers of children with ASD earn fifty-six percent less, are six percent less likely to be employed, and work seven fewer hours each week); Joan C. Williams & Stephanie Bornstein, *The Evolution of “Fred”: Family Responsibilities Discrimination and Developments in the Law of Stereotyping and Implicit Bias*, 59 HASTINGS L.J. 1311, 1311–12 (2008) (describing impact of litigation against employers who fire employees with family responsibilities); Elizabeth T. Powers, *New Estimates of the Impact of Child Disability on Maternal Employment*, 91 AM. ECON. REV. 135, 137 (2001) (finding from national dataset that significantly fewer mothers of disabled children are in the labor force than are mothers of other children); NAT’L ALLIANCE FOR CAREGIVING & AARP, CAREGIVERS OF CHILDREN: A FOCUSED LOOK AT THOSE CARING FOR A CHILD WITH SPECIAL NEEDS UNDER THE AGE OF 18, at 8 (2009), available at http://www.caregiving.org/data/Report_Caregivers_of_Children_11-12-09.pdf (stating that just over half of parents caring for special needs children are employed, compared with over sixty percent in the general population; seventy-five percent report making changes in employment situation because of caregiving, including reducing hours and leaving work).

prior year.²⁶ The hearing officer disagreed somewhat with both parties, and, in November, he ordered that Susie's IEP be revised to include a half-day of kindergarten, during which she would receive tutoring and speech therapy, as well as five hours per week of PRT. The combination of repeating kindergarten and the additional services appeared to work. By the end of the school year, Susie had learned most of what she needed to begin first grade. Her repetitive behaviors had decreased in frequency and intensity, but she had begun to leave school without letting anyone know.²⁷ The next annual IEP meeting focused on strategies for managing Susie's newest behavior.

II. BOTH FAMILIES TREATED LEGALLY

Despite how differently these two families experienced early intervention, preschool, and early elementary school, each family's experience complied with the requirements of the Individuals with Disabilities Education Act of 2004 (IDEA).²⁸

Because Charlie and Susie were diagnosed when they were younger than three, both were eligible for early intervention services under the IDEA.²⁹ Once a child is evaluated and found to be in need of services, the responsible agency working with the child's family provides services under an IFSP designed to meet the "unique needs of the [child] and the family."³⁰ In each case, the local department arranged for the child and family to be evaluated to determine whether the child had a disability and whether the child would benefit from services.³¹

Both children received services commonly offered to children with similar issues.³² The health department responsible for Child

26. 20 U.S.C. § 1415(j) (2006).

27. Connie Anderson et al., *Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders*, 130 *PEDIATRICS* 870, 870 (2012), available at <http://pediatrics.aappublications.org/content/early/2012/10/02/peds.2012-0762.full.pdf+html> (explaining that nearly half of parents with autistic child age four or older reported at least one incident of their child leaving a safe location).

28. 20 U.S.C. § 1400 (2006) *et seq.*

29. 20 U.S.C. § 1432(4)(A); *see also* Rothstein & Irzyk, *supra* note 3, § 2:13 (giving overview of Early Intervention in IDEA); Bitterman et al., *supra* note 22, at 1512–13 (noting that in a national sample, parents of children with ASD became concerned about their child's problems shortly before second birthday and children, on average, were 19.6 months when they began to receive services).

30. 20 U.S.C. § 1436(d)(4) (2006).

31. *See* 20 U.S.C. § 1436(a) (2006).

32. *See* Bitterman et al., *supra* note 22, at 1513–14 (stating that the most common services are speech therapy, occupational therapy, behavioral management programs, learning assistance and study skills, and service coordination or case management).

Find services for Charlie and his family developed a plan that met the literal terms of the statute in that the IFSP was tailored to meet Charlie's therapeutic needs in the context of his family. That is, therapies were identified to address the symptoms of Charlie's autism, help him develop speech, and achieve some social skills.³³ His parents were also provided with assistance in learning about what would help Charlie develop and improve.³⁴ Through the organization of the center and the center's listserv, they gained access to support systems, information, and skills.³⁵

The local department in Susie's county focused more narrowly on Susie's needs and did not focus on issues confronting Susie's family. Under the IFSP, Susie's needs were to be met through therapy in Susie's home with Susie's parents in attendance. While the ABA hours were limited, and the IFSP did not afford Susie's parents the breadth of assistance available to Charlie's parents, the IFSP was probably adequate under IDEA. The law does not require that Susie receive services that allow her to maximize her potential.³⁶ Instead, she need only receive "some benefit."³⁷ Further, Susie's parents could receive some of the help they needed at the same time Susie was receiving services because the plan provided for therapy in Susie's home in the presence of Susie's parents. In the course of her work with Susie, the therapist could help Susie's parents learn more about how to work with Susie.³⁸

33. An ISFP is adequate if it provides a meaningful benefit to the child. *See Adams v. State*, 195 F.2d 1141, 1149–50 (9th Cir. 1999).

34. A department may include within an ISFP family training "to assist the family of an infant or toddler with a disability in understanding the special needs of the child and enhancing the child's development." 34 C.F.R. § 303.13(b)(3) (2013).

35. The ISFP may also include technical assistance. 34 C.F.R. § 303.13.(b)(1)(ii)(E) (2013).

36. *See A.G. v. Frieden*, 2009 WL 806832, at *11 (S.D.N.Y. Mar. 26, 2009); Womack, *supra* note 16, at 216–24 (describing issues under IDEA around identifying adequate services for child on autism spectrum). There is a possibility, however, that the health department plan had a policy of providing only ten hours a week of ABA in all cases, regardless of the individual situation of the child and family. If Susie's parents could show that the department would not provide more hours of ABA regardless of Susie's situation, such "predetermination" would violate the Act. *See Deal v. Hamilton Cnty. Bd. of Educ.*, 392 F.3d 840 (6th Cir. 2004); *Battle v. Pennsylvania*, 629 F.2d 269, 280 (3d Cir. 1980) (discussing a state law that limits education services to 180 days a year violates EAHRC for denial of individual consideration of child's unique needs); *S.W. v. Warren*, 528 F.Supp.2d 282, 295–96 (S.D.N.Y. 2007) (stating that where a school limited amount, duration, and availability of services to all children with autism, parents were not required to exhaust administrative remedies under IDEA); LAURA ROTHSTEIN & JULIA ROTHSTEIN, *DISABILITIES AND THE LAW* § 2.20, n.17 (2009).

37. *See Bd. of Educ. of Hendrick Hudson Cent. Sch. Dist. v. Rowley*, 458 U.S. 176, 203 (1982) (White, J., dissenting); *Adams v. State*, 195 F.2d 1141, 1149–50 (9th Cir. 1999).

38. States have flexibility to service family needs in a variety of ways. *See* 34 C.F.R. § 303.13(b)(3) (2013) (authorizing family training to help family understand child's special

Each child experienced two transitions before entering the first grade. The first transition was from early intervention services to preschool. The second was from preschool to kindergarten. The law requires that the child be provided with a “smooth and effective transition” from early intervention into preschool,³⁹ but the statute does not detail what that means. The agency providing early intervention services is required to convene a meeting including its representative, the parents, and the school system to discuss the services the child will be provided.⁴⁰ Further, by the time the child turns three, planning for the child’s IEP must have begun.⁴¹

While the children and their families were treated quite differently at each of these transitions, both systems arguably complied with the law. Charlie’s transitions from early intervention to preschool and then to kindergarten were seamless because the local agencies worked closely together and shared access to the center, which served as the hub for therapeutic, educational, and parent support services. Charlie’s parents participated in meetings about planning the transition, but they were not expected to initiate them, and the agencies fully shared information and planning resources with each other and with Charlie’s parents.

In Susie’s county, transitions had to be accomplished in a system in which the local agency providing the early intervention services did not have an ongoing integrated process with the agency providing the educational services. As a result, planning Susie’s transition was more difficult. Because the local agency responsible for early intervention services made only the minimal effort required under the statute, Susie’s parents had to take greater responsibility for initiating the process with the school to plan for preschool. Once the school system received the request for services, it took the necessary steps to work with Susie’s parents to develop the IEP.

The law does not require that the preschool IEP build on the IFSP, so long as the IEP is designed to provide an educational benefit to the child. Susie’s preschool IEP was quite different from her early intervention services, and the school system expressly rejected her parents’ demand that Susie continue to receive ABA. Children on the autism spectrum often experience unusual difficulties with change.⁴² In Susie’s case, the proposed IEP would change therapeutic approaches, the location where Susie would receive services, and

needs and help child develop); 34 C.F.R. § 303.13(a)(4), § 303.13(d) (noting that other services also satisfy requirement that states help the families).

39. 20 U.S.C. § 1412(a)(9) (2006).

40. 20 U.S.C. § 1437(a)(9)(ii)(II) (2006); 34 C.F.R. § 303.211(b)(6)(ii)(B) (2013).

41. 20 U.S.C. § 1412(a)(9) (2006).

42. See AMERICAN PSYCHIATRIC ASS’N, *supra* note 7.

the people providing services. As discussed earlier, however, there are limits on what the school system is required to do. Helping Susie avoid problems arising out of the changes in therapy and location is beyond those requirements so long as the plan is reasonably calculated to enable the child to receive some educational benefit.⁴³

While Susie's treatment was mostly likely legal under IDEA, Susie's preschool plan is most vulnerable to a legal challenge on the grounds that it does not provide for her to be educated in the "least restrictive environment."⁴⁴ Children on the autism spectrum often experience substantial challenges in terms of social skills, emotional outbursts, repetitive behaviors, and tendencies to run away when unsupervised.⁴⁵ School systems, therefore, may be inclined to place them in a specialized classroom rather than in general education because most schools lack the kind of backup resources that Charlie's school provides.⁴⁶ The specialized classroom, however, may deprive the child of access to the highest level of academic work that he or she can accomplish. It may also deny the child opportunities to develop social skills and work on reducing troubling behaviors in a more diverse setting.⁴⁷

Since parents are the ones who live with the child's troubling behaviors and social problems, parents experience losses along with their children. Beyond the challenges of daily living, parents experience the profound anxiety of knowing that their child's problems might diminish or even eliminate the child's capacity to function independently in the world. Parents are likely to feel responsible, therefore, for doing whatever they can to prepare their child for adulthood or independence, regardless of whether the school is

43. See *Rowley*, 458 U.S. at 206–07; Mark C. Weber, *Common-Law Interpretation of Appropriate Education: The Road Not Taken in Rowley*, 41 J.L. & EDUC. 95 (2012) (explaining and critiquing *Rowley*); ROTHSTEIN & IRZYK, *supra* note 3, at § 2:20.

44. See *L.B. ex rel. K.B. v. Nebo Sch. Dist.*, 379 F.3d 966, 976 (10th Cir. 2004); see also 20 U.S.C. § 1412(a)(5)(A) (2006) (providing a definition for least restrictive environment); 34 C.F.R. § 300.114(a) (2013) (creating an obligation for public agencies to educate children with disabilities in the least restrictive environment); Seligmann, *supra* note 10, at 285–86; Roberts, *supra* note 24, at 1054–55.

45. PAUL LAW & CONNIE ANDERSON, INTERACTIVE AUTISM NETWORK, KENNEDY KRIEGER INST., IAN RESEARCH REPORT: ELOPEMENT AND WANDERING (Apr. 20, 2011), available at http://www.iancommunity.org/cs/ian_research_reports/ian_research_report_elopement; Anderson et al., *supra* note 27, at 872–73; *supra* text accompanying notes 13, 24, 27.

46. See Nicole Jorwic, *Autism and Elopement Behaviors*, SPECIAL EDUC. L. BLOG (Dec. 17, 2009), <http://blog.foxspecialdlaw.com/2009/12/autism-and-elopement-behaviors.html>; Bitterman et al., *supra* note 22, at 1515 (stating that children with ASD were more likely than other children in special education to spend time in segregated classrooms).

47. See Bitterman et al., *supra* note 22, at 1515 ("Given that social deficits are a core feature of autism, time spent with typical peers is usually seen as a critical component to improve social skills of young children with ASD.").

helping. Without help from the school, that task becomes all the more difficult.

Although the transition from early intervention to preschool is considered an important point in the child's progress under the statute, nothing in the statute requires the school system to provide services during the transition if there is a conflict about the child's IEP.⁴⁸ Susie's parents were therefore treated legally during their challenge to Susie's IEP. While IDEA provided them with rights to statutory due process,⁴⁹ their objections were ultimately rejected. In the meantime, Susie received no services from the early intervention program or in the preschool setting. Susie's parents, therefore, had to contend with two challenges: advocating for their position about what is right for Susie in the school system and taking care of Susie during the hours when she could have been in school.⁵⁰ This can make challenging an IEP extremely costly for families like Susie's.

The transition from preschool to kindergarten, on the other hand, is subject to a "stay-put" requirement, under which the child must be allowed to continue in his or her current educational placement while the parents and school system resolve conflicts about what should happen next.⁵¹

48. 20 U.S.C. § 1415(j) (2006); 34 C.F.R. § 300.518(c) (2013); see JOY MARKOWITZ ET AL., PRESCHOOLERS WITH DISABILITIES: CHARACTERISTICS SERVICES AND RESULTS 57 (2006) (finding that nearly one-third of children transitioning from early intervention to preschool services experienced a gap in service, with the gap averaging five months; however, the Presidential Commission recommended continuing service in 2002); Sheryl Dicker & Emily Bennett, *Engulfed by the Spectrum: The Impact of Autism Spectrum Disorders on Law and Policy*, 45 VAL. U. L. REV. 415, 443-44 (2011) (describing conflicting decisions about stay-put requirement when children age out of early intervention). Compare *D.P. ex rel. E.P. v. Sch. Bd. of Broward Cnty.*, 483 F.3d 725, 729-30 (11th Cir. 2007) (explaining that there is no obligation to maintain IFSP services during pendency of dispute over IEP) and *M.M. ex rel. A.M. v. N.Y.C. Dep't of Educ.*, 583 F. Supp. 2d 498, 512 (S.D.N.Y. 2008) (stating that a stay-put provision was inapplicable where a child was in transition from early intervention services to school) with *Pardini v. Allegheny Intermediate Unit*, 420 F.3d 181, 186 (3d Cir. 2005) (explaining that making transition from early intervention to school "smooth and effective" requires maintenance of IFSP services during pendency of dispute over IEP).

49. See 20 U.S.C. §§ 1435(c)(2)(A)(ii)(II), 1439(a)(1), 1439(a)(5), 1415(c)(2)(A) (2006); 34 C.F.R. § 303.421(b)(3) (2013).

50. Susie's parents could have enrolled her in a private preschool with a program for a child on the autism spectrum and sought reimbursement from the school district. Doing so, however, assumes they have the financial resources to pay tuition and wait for reimbursement. Further, self-help is risky because the school is not responsible for reimbursement in many circumstances.

51. 20 U.S.C. § 1415(j) (2006).

III. SPECIAL EDUCATION AND SPECIAL PARENTS

Before federal law required schools to be open to children with disabilities, millions of children were denied access to free and appropriate education.⁵² Parents could try to educate them at home, place them in institutions, or pay for educational opportunities in special settings.⁵³ With the passage of the Education for All Handicapped Children Act of 1975, a precursor to the IDEA,⁵⁴ parents gained the right to have public schools provide appropriate education to their children with disabilities without paying for that education.⁵⁵ Without a doubt, children with disabilities are better off now, as are their parents.

What remains, however, are grave problems about the burdens on parents when a child needs access to special education. Stresses around accessing appropriate educational resources occur in the context of other changes in social, economic, and medical practices that have, over the last half-century, amplified parental responsibilities for the care of their children. Changes include longer lifespans for children with disabilities and chronic illnesses, less institutionalization for younger children with disabilities, more parents raising children alone, increased market participation by all parents, and the development of complex daily medical regimes managed by parents of children with disabilities and chronic illnesses.⁵⁶

From the perspective of addressing the burdens on parents, special education practices under current law lack standards in two essential areas. First are practices that support parental competence. Second are practices that conserve parental resources.

Practices affecting parental competence and conserving parental resources are visible in each of the three stages of special education, as the stories of Charlie's and Susie's families demonstrate. First is the "diagnostic" phase, when the parents seek to have a child evaluated for services. If the child is found eligible, the second stage, plan development, begins. This stage involves parents participating with early intervention or school personnel to develop, or at least agree to, a service plan, called either an Individualized Education

52. See *supra* note 2.

53. *Id.*

54. Pub. L. No. 94-142, 89 Stat. 788-89 (1975), amended by The Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 1400; see ROTHSTEIN & IRZYK, *supra* note 3, at §§ 2:3-2:5 (history of EAHC and IDEA).

55. See generally Bd. of Ed. of Hendrick Hudson v. Rowley, 458 U.S. 176, 179-85, 191-92 (1982) (providing a history of federal law regarding provision of special education); Turnbull, Shogren & Turnbull, *supra* note 2 (reviewing how parental involvement impacted growth of access to special education).

56. See *infra* notes 223-27.

Program (IEP) or Individualized Family Service Plan (IFSP), depending on the child's age. Assuming an IEP or IFSP is put into place, the third stage, monitoring, starts. During this stage, parents monitor whether the plan is being followed, whether it works, and whether modifications are necessary.⁵⁷ Problems can arise at every stage, and parents can use informal or formal mechanisms to try to resolve them.⁵⁸

The IDEA does not mandate practices for each stage, but, if they object to a decision, parents are entitled to due process, including notice and an opportunity for a hearing at which the parents can participate.⁵⁹ As the experiences of Charlie's parents and Susie's parents demonstrate, practices may be more or less parent-friendly or parent-oriented. Charlie's parents encountered practices designed to take their needs into account on most levels, while Susie's parents did not. What seems plain from descriptions and studies of special education is that Susie's parents' experience is more typical.⁶⁰ The result is a set of problems that can overburden parents who are trying to raise a child with special needs while staying connected to family and friends, remaining economically productive, and maintaining their health and emotional well-being.

What separates the experiences of Charlie's parents from the experiences of Susie's can be summarized in two words: competence

57. See David Ferster, *Broken Promises: When Does a School's Failure to Implement an Individualized Education Program Deny a Disabled Student a Free and Appropriate Public Education*, 28 BUFF. PUB. INT. L.J. 71 (2009–10).

58. 20 U.S.C. §§ 1435(c)(2)(A)(ii)(II), 1439(a)(1), 1439(a)(1)–(8), 1415(c)(1) (2006); 34 C.F.R. §§ 303.421(b)(3) (2013); see ROTHSTEIN & IRZYK, *supra* note 3, at §§ 2:34–2:43 (offering an overview of dispute resolution under IDEA); Elisa Hyman et al., *How IDEA Fails Families Without Means: Causes and Corrections from the Frontlines of Special Education Lawyering*, 20 AM U. J. GENDER SOC. POL'Y & L. 107, 118–20 (2011) (describing steps for parents to establish and challenge IEP); Pasachoff, *supra* note 1, at 1422–24 (stating that between 3,000 and 7,000 due process hearings are held annually, with up to 400 proceeding to litigation; approximately 4,000 mediations held annually; approximately 6,000 complaints filed annually with states). Relatively little litigation occurs. See Samuel R. Bagenstos, *Where Have All the Lawsuits Gone?, The Shockingly Small Role of the Courts in Implementing the Individuals with Disabilities Education Act 8–9* (Wash. Univ. Sch. of Law Working Paper No. 08-12-05, 2008), available at <http://ssrn.com/abstract=/1302085>; ONG-DEAN, *supra* note 4 (noting that relatively few parents seek due process hearings, and most of those are privileged in terms of cultural and economic capital).

59. ROTHSTEIN & IRZYK, *supra* note 3, at §§ 2:34–2:43.

60. See ONG-DEAN, *supra* note 4, at 3–4, 115–16 (noting that parental interests are less influential than interests of professionals in school system and of budgetary needs of system); Schaffer v. Weast, 546 U.S. 49, 65–67 (2005) (Ginsburg, J., dissenting) (noting that for budgetary reasons, school boards will favor educational programs that put least strain on budget, and that, further, most parents lack the knowledge and sophistication to mount an effective opposition); Donald B. Bailey, Jr. et al., *Promoting Family Outcomes in Early Intervention*, in HANDBOOK OF SPECIAL EDUCATION 675 (James M. Kauffman & Daniel P. Hallahan eds., 2011) [hereinafter *Promoting Family Outcomes*] (discussing the rarity of IFSPs that focus on family rather than exclusively on child).

and resources. Charlie's parents were provided with support to see and develop themselves as competent parents, while Susie's were not. Charlie's parents could continue to produce and develop economic, emotional, and social resources while meeting Charlie's needs, while Susie's parents saw their resources depleted.

A. Supporting Competence

All conscientious parents find themselves doubting their competence, often from the first moment after a child is delivered. Most find ways to manage their self-doubt, usually with help from partners, parents, friends, doctors, and other professionals, as well as child-raising advice in various media. If a parent loses his or her way, however, the consequences can be severe, including depression and desertion, with sometimes devastating consequences for the child.⁶¹

The moment when a child is diagnosed with a serious disability or chronic illness is another moment when, for most parents, self-doubt is likely to be severe.⁶² Partners, relatives, and professionals can provide some help, as can media sources, but the parents of special needs children are in an unusual situation. Their experiences are uncommon, and sources of help may not be readily available.⁶³ In the absence of adequate support, parents may feel paralyzed by their sense of incompetence, and their lack of information and skill may impede the child's development or even result in harm to the child.⁶⁴

Charlie's parents were served by local agencies in ways that helped them develop skills and gave them reason and opportunity

61. See Donald B. Bailey et al., *Recommended Outcomes for Families of Young Children with Disabilities*, 28 J. EARLY INTERVENTION 227, 230–31 (2006) [hereinafter *Recommended Outcomes*]; Neely-Barnes & Dia, *supra* note 5, at 93; Heidi P. Perryman, *Parental Reaction to the Disabled Child: Implications for Family Courts*, 43 FAM. CT. REV. 596, 600–04 (2005) (describing range of problems experienced by special needs children whose parents lack capacity to meet child's needs, including desertion by the parents).

62. See Perryman, *supra* note 61, at 600–01 (describing psychological reactions of parents upon learning about a child's disabling condition, such as grief and anxiety). See generally T. BERRY BRAZELTON AND BERTRAND G. CRAMER, *THE EARLIEST RELATIONSHIP: PARENTS, INFANTS AND THE DRAMA OF EARLY ATTACHMENT* (1991).

63. See *Newly Diagnosed*, INTERACTIVE AUTISM NETWORK, http://www.iancommunity.org/cs/newly_diagnosed/ (last visited Nov. 22, 2013) (offering advice for parents about how to cope with an autism diagnosis, particularly when parents may be feeling "both devastated and panicked"). See generally ANDREW SOLOMON, *FAR FROM THE TREE* (2012); NAT'L ALLIANCE FOR CAREGIVING & AARP, *supra* note 25, at 9–10 (finding that sixty-seven percent of caregivers reported using internet for caregiving information, with eighty-one percent seeking information about the child's condition).

64. See Perryman, *supra* note 61, at 600–01.

to view themselves as competent. First, the center gave parents access to expert information without demanding that they become experts themselves. Parents were also provided with the opportunity to participate in therapy sessions. Staff shared information and suggestions about managing Charlie when he was not in school. When Charlie was old enough for preschool and then for school, staff members helped to evaluate his readiness and offered insight about how to manage the transition successfully.

Second, center staff demonstrated respect for parents. The staff asked Charlie's parents what they thought Charlie was experiencing and what he needed. Their questions were authentic efforts to discover what Charlie was about, not matters of formality.⁶⁵ Changes were made to Charlie's program based on parental feedback, which reinforced his parents' sense that their knowledge about their child was useful and important.

Third, the center's program brought parents together. Each could learn from the others about what was happening to their children. They could support each other when something happened in the center or when another child caused concerns. Just as important, each parent could work with the others to seek changes in policies and practices affecting their children.

Parents who develop greater competence in an objective sense and a stronger appreciation for their own competence can have a positive influence on their children's social, cognitive, physical, and emotional development.⁶⁶ They can also contribute to a child's educational success because their enhanced knowledge and confidence may make them more active and effective participants in the special education process.⁶⁷ They may be less intimidated by professionals, both in and outside of the school system, who suggest educational or treatment plans that they do not consider appropriate for their child. Objective and subjective competence may be of particular importance to parents who bring fewer social, educational, and economic resources into the process. In the present system, these parents generally participate less in educational settings, and their children often receive less attention, fewer resources, and achieve

65. Cf. Engel, *supra* note 4, at 189–90 (describing parents as not perceiving their input as being important to decisionmakers in IEP meetings and not having necessary expertise in pedagogy; describing teaching professionals as not perceiving parents to be making important contributions in IEP meetings).

66. See Neely-Barnes & Dia, *supra* note 5, at 93 (explaining that parents of special needs children who have positive image of self and child experienced less stress).

67. See ONG-DEAN, *supra* note 4, at 95–113 (professionals on IEP teams found to pay greater attention to opinion of parents where parents more highly educated and highly resourced).

less success in special education than children of more privileged parents.⁶⁸

B. Conserving Resources

The second major difference between the experience of Charlie's and Susie's parents is that Charlie's parents' resources were conserved, while Susie's parents' resources were depleted. Resources, in this context, means time, energy, and money.

Parents of special needs children, like all parents, require enough money to support their family, enough human contact to support their souls, and enough emotional strength to cope with life's challenges. Many parents of special needs children find that satisfying those requirements demands an unusual amount of time, energy, and money. Educational institutions cannot, of course, guarantee that parents of special needs children can get and keep employment, maintain relationships with family and friends, or enjoy emotional stability and physical health. What they can do, however, is make organizational choices that increase the possibility that parents can conserve the resources they have.⁶⁹

For example, children on the autism spectrum, like Charlie and Susie, are likely to have meltdowns, at least occasionally, both at school and at home.⁷⁰ If the school lacks the capacity to handle the child during a meltdown, a call may go out to the parents to come and get the child. Alternatively, a school like Charlie's can look to the center for help and may not have to call his parents. Charlie's parents get the benefit of emotional support because they know that the familiarity and predictability of the center is comforting to Charlie. They also get the benefit of indirect financial support because neither has to leave work to pick up Charlie, lose pay for the day, or risk losing their job because of their unexpected absence.

68. See *id.* at 113–60 (discussing how the decision to seek due process hearings, the nature of participation in hearings, and the impact of the hearing examiner differ depending on cultural and economic capital of parents).

69. While I am arguing for the conservation of parental resources, others have argued for programs that pursue the greater objective of enhancing parental resources. See Jeanne Brooks-Gunn et al., *Early Childhood Intervention Programs: What About the Family?*, in HANDBOOK OF EARLY CHILDHOOD INTERVENTION 549, 553–62 (Jack P. Shonkoff & Samuel J. Meisels eds., 2000) (surveying literature on early childhood programs evaluated for whether they enhanced parental resources in terms of parenting capacity, education, employment, mental health, etc.).

70. See FRED R. VOLKMAR & LISA A. WIESNER, A PRACTICAL GUIDE TO AUTISM: WHAT EVERY PARENT, FAMILY MEMBER AND TEACHER NEEDS TO KNOW 273–74 (2009). See generally GEOFF COLVIN AND MARTIN R. SHEEHAN, MANAGING THE CYCLE OF MELTDOWNS FOR STUDENTS WITH AUTISM SPECTRUM DISORDER (2012).

They can conserve their social support network because they do not need to call on a grandparent or friend to help Charlie.

When Susie suffers a meltdown, her teacher has two alternatives, both of which are unsatisfactory to Susie's parents. The school can call Susie's parents to pick her up, but their response will prove costly in terms of time, energy, and money. Alternatively, the teacher can attempt to handle the meltdown, but the teacher may lack training or competence. In some instances, children have been inappropriately restrained, which can be risky for the child physically and might make the child reluctant to attend school.⁷¹ Knowing that a school cannot meet Susie's needs or that someone might try to restrain her imposed yet another emotional burden on her parents. The frequent calls from the school eventually cost them a job.

Charlie's and Susie's families also experienced differences in how much time and energy they had to expend to accomplish the transition from early intervention into preschool. Charlie's parents expended almost no resources because Charlie's transition was seamless, involving no changes in the therapeutic approach, parental involvement, or program location. It was also well organized in terms of information shared between the early intervention and school programs, and the parents were kept fully informed and involved throughout. At the end, Charlie experienced no gap in services.

Susie's experience was quite different. While the Child Find worker initiated the process of transitioning Susie into preschool, her parents had to do more of the information gathering and service coordination than Charlie's parents had to do. They also had to develop expertise in what Susie might need in order to advocate for her. The treatment plan proposed a different therapeutic approach than had been used previously, and the proposed services

71. See Ebonie S. *ex rel.* Mary S. v. Pueblo Sch. Dist. 60, 819 F.Supp.2d 1179 (D. Colo. 2011) (discussing a "wrap-around" desk used to restrain a kindergarten child when she exhibited out of control behavior); Minnis *ex rel.* Doe v. Sumner Cnty. Bd. of Educ., 804 F. Supp. 2d 641, 648 (M.D. Tenn. 2011) (discussing a teacher who grabbed a four-year-old autistic child around the arm and restrained him by holding his head hard enough for the child to report being hurt); Elizabeth Loefgren, *The Missing Piece of the Autism Jigsaw Puzzle: How the IDEA Should Better Address Disciplinary Procedures*, 35 LAW & PSYCHOL. REV. 225, 233-34 (2011) (providing examples of inappropriate and harmful attempts by teachers and police to control children having tantrums or meltdowns); Lieutenant Colonel Elizabeth L. Schuchs-Gopaul, USAF, *Twelve Things Every JAG Should Know: Legal Issues Facing Military Families with Special Needs Children*, 38 REPORTER 20 (2011) (cautioning military personnel to avoid signing an IEP permitting the school to restrain the child since the authority could be misused); Nirvi Shah, *Kansas Takes First Step Toward Regulating Restraints, Seclusion*, EDUCATION WEEK, ON SPECIAL EDUCATION (Apr. 23, 2012), http://blogs.edweek.org/edweek/speced/2012/04/kansas_takes_first_step_toward.html.

involved new people as well as a new location, all conditions that could prove especially difficult for a child on the autism spectrum. When Susie's parents objected to the proposed plan and nothing was agreed upon before she turned three, there was no plan for continuing services. As a result, Susie was without any treatment at all for a period of months.

While Charlie was the direct beneficiary of the well-organized transition he experienced from early intervention services into pre-school, he was not its sole beneficiary. His parents benefitted as well because the practices helped them to conserve their resources of time, energy, and money. Susie, on the other hand, suffered and was not the only person to be harmed by a system whose parts failed to coordinate fluidly with each other and with Susie's parents. Her parents suffered as well in terms of time, energy, and money spent on a process that could have been more helpful to Susie while, at the same time, being more respectful of the needs of her parents.

IV. PARENT-ORIENTED REFORMS

If special education practices were changed to serve the needs of children while also supporting parental competence and conserving parental resources, special education would look rather different from the present regime. While the experiences of Charlie and his parents probably represent a gold standard that is beyond the capacity of many public education systems, they suggest at least three relatively affordable reforms. These three changes are presented here in the order of their affordability, from the least expensive to the most. First, Subsection A suggests that all schools should put parents in touch with each other. Second, Subsection B argues that schools should be required to propose specific educational plans for the most common special education situations through a public process and to commit to providing the uniform plan to all children in the same situation. Third, Subsection C advocates for preferring universal design principles in general education.

A. Put Parents in Touch with Each Other

Both Charlie's and Susie's parents experienced isolation from friends, family, and community after their children began exhibiting autistic behaviors. Isolation imposes significant consequences

on families of children with disabilities. Among other things, isolated parents have fewer opportunities to learn about what their children are experiencing or what might help them.⁷² Their isolation can also drain them emotionally, putting their relationships in jeopardy.⁷³ Lacking advice and input from others, they may make choices for their child and themselves that are inadvisable or miss chances to improve their child's situation. Isolation of parents also deprives them of chances to work with others in the community to improve the situation of their children.

One way to put parents in touch with each other is to imitate the program of the center that Charlie attended: create times and places for parents to have face-to-face encounters, help them develop friendships and alliances, and give them opportunities to discuss shared experiences. This is the model of parent-teacher organizations at many schools.⁷⁴ It works well in many general education settings, and the model should work in special education settings.⁷⁵ In fact, federal funding is available to fund parent information centers.⁷⁶

Face-to-face organized meetings are not the only method for helping parents meet each other, exchange information, and develop alliances. Indeed, for some parents raising special needs children, finding time and energy even to take advantage of helpful activities is out of the question. Another model involves using social media and email to invite interested parents to communicate with one another at times that are convenient for them.⁷⁷

72. See COUNCIL OF PARENT ATTORNEYS & ADVOCATES, *Parent or Family Member*, <http://www.copaa.org/?Parent> (last visited Nov. 22, 2013) (advising parents of the importance of networking to improve their advocacy around special education); Carole Brown, Samara Goodman & Lisa Küpper, *The Unplanned Journey: When You Learn That Your Child Has a Disability*, NAT'L INFO. CTR. FOR CHILD. AND YOUTH WITH DISABILITIES NEWS DIG. 7, 8 (3d Ed., 2003), available at http://www.familyvoices.org/admin/work_caring/files/nd20.pdf (emphasizing importance of communication with other parents for benefit of both child and parent; noting helpfulness of Parent Training and Information Centers for when parent wants to connect with other parents).

73. See JANELLE HILL & DON PHILPOTT, *SPECIAL NEEDS FAMILIES IN THE MILITARY: A RESOURCE GUIDE* 234–36 (raising a special needs child can be highly emotional; identifies resources available to parents in the military, with emphasis on peer support, including parent-to-parent programs, and importance of avoiding isolation).

74. See NAT'L PTA, *National Standards for Family-School Partnerships*, <http://www.pta.org/programs/content.cfm?ItemNumber=3126> (last visited Nov. 22, 2013).

75. See NAT'L PTA, *Starting a Special Education PTA*, <http://www.pta.org/members/content.cfm?ItemNumber=2100> (last visited Nov. 22, 2013).

76. 20 U.S.C. § 1471(a) (2006); see 78 Fed. Reg. 24,395 (announcing grants for 2013 for Parent Training and Information Centers; emphasizing importance of "strengthening the ability of parents to participate fully in the education of their children").

77. See Susanna Fox, Maeve Duggan & Kristen Purcell, *Family Caregivers Are Wired for Health*, PEW INTERNET (June 20, 2013), available at <http://www.pewinternet.org/Reports/2013/Family-Caregivers/Summary-of-Findings.aspx> ("[C]aregivers are more likely than other

One example of the web-based communication approach that may serve as a model is the listserv available to members of military communities who have children with special needs.⁷⁸ Because military families are subject to transfers from place to place, they have an unusually great need for information about resources in new communities.⁷⁹ Making decisions from a distance about schools, medical providers, and housing is difficult for all families, but those decisions are particularly fraught for a family with a special needs child.⁸⁰ The military recognizes these difficulties in a variety of ways, including, in many circumstances, not requiring the assignment of a member of the military to a location where the educational or medical needs of a special needs child cannot be met.⁸¹ For this reason, obtaining information about the services available on a distant base may be vital to the welfare of a family with a special needs child. In theory, when a transfer is contemplated, parents should be able to get information about the proposed location through the staff of the Exceptional Family Member program at the new location.⁸² In practice, while every base has an Exceptional Family Member program, the adequacy of staffing and services varies by base.⁸³

Military parents, however, have an additional resource: a facilitated listserv intended to help parents share information about

adults to . . . go online to find others with similar health concerns”; “52% of caregivers with internet access say that online resources have been helpful to their ability to cope with the stress of being a caregiver.”); NAT’L ALLIANCE FOR CAREGIVING & AARP, CAREGIVING IN THE U.S. 69 (2004) (finding that about a third of caregivers use the internet “as a coping mechanism,” and of those, thirty-nine percent use it to “look for support or advice from other caregivers”). A number of advocacy and education groups use the internet to communicate with parents about special education. *See, e.g.*, NAT’L CENTER FOR LEARNING DISABILITIES, <http://www.nclld.org> (last visited Jan. 11, 2014); EDUC. L. CENTER, <http://www.edlawcenter.org> (last visited Jan. 11, 2014); WRIGHTSLAW, <http://www.wrightslaw.com> (last visited Jan. 11, 2014).

78. *See infra* notes 84–89 and accompanying text.

79. *See id.*

80. *See* U.S. GOV’T ACCOUNTABILITY OFFICE, GAO-12-680, MILITARY DEPENDENT STUDENTS: BETTER OVERSIGHT NEEDED TO IMPROVE SERVICES FOR CHILDREN WITH SPECIAL NEEDS (2012); Jeremy Hilton, *The Military Child and Special Education*, EXCEPTIONAL PARENT MAG., Sept. 2009, at 78, available at <http://www.wrightslaw.com/info/mil.child.sped.exc.parent.pdf>; Emma Brown, *Military Helps Families Find Care for Special-Needs Kids*, WASH. POST, Dec. 28, 2009, at B01.

81. U.S. DEP’T OF DEF., INSTRUCTION NO. 1315, AUTHORIZING SPECIAL NEEDS FAMILY MEMBERS TRAVEL OVERSEAS AT GOVERNMENT EXPENSE § 5.4.6 (Dec. 20, 2005). The same policy and practices are applied to domestic transfers. U.S. GOV’T ACCOUNTABILITY OFFICE, *supra* note 80, at 9, n.10; *see also* Brown, *supra* note 80; Schuchs-Gopaul, *supra* note 71.

82. U.S. GOV’T ACCOUNTABILITY OFFICE, *supra* note 80; Schuchs-Gopaul, *supra* note 71.

83. U.S. GOV’T ACCOUNTABILITY OFFICE, *supra* note 80.

educational and medical services for their special needs child.⁸⁴ Among the many subjects discussed by more than 1,200 participants on the listserv are transfers.⁸⁵ For example, a parent can post an inquiry to the listserv about the proposed location of reassignment, and parents who know the place can contribute in response. Sometimes a responder advises the parent to decline the transfer because the proposed location lacks appropriate resources.⁸⁶ Sometimes the response is more nuanced, such as advice about seeking housing where the school system has appropriate programs or arranging for medical care at a facility that can provide suitable care.⁸⁷ Postings to the listserv also come from experts who are asked to comment on matters such as a particular form of educational or medical intervention for a child.⁸⁸ The listserv manager often posts references to helpful reports and websites.⁸⁹

The military's facilitated listserv is the kind of innovation that supports parental competence while conserving parental resources. In terms of competence, parents in need of information can use the listserv to find answers in real time to perplexing questions. Further, parents who have information to share may gain greater confidence in their own competence as parents because they have advice of value to other parents.

The listserv also helps parents conserve resources by making information readily available. Rather than use their time researching possible solutions to problems, parents can turn to the listserv to get information and ideas from other parents who have experienced similar problems. Sometimes, input from other parents and experts on the listserv can help parents avoid reinventing the wheel or pursuing unpromising solutions. It also provides access to expert advice, which can save parents the time and effort required to find their own experts, research the issues, and evaluate solutions. When parents are considering what kind of plan to seek for their child, listserv participants can help identify what the local school system is likely to suggest for the IEP, something most school systems do not

84. The listserv is a project of "STOMP - Specialized Training of Military Parents," a nonprofit that receives funding from, among other sources, the U.S. Department of Education. The website can be found at STOMP, <http://www.stompproject.org> (last visited Jan. 11, 2014). An overview video is available at *STOMP Overview Video*, YouTube (June 4, 2012), <http://www.youtube.com/watch?v=PA00U7tGqTQ&feature=youtu.be>.

85. Telephone Interview between Lauren West and Heather Hebdon, Founder and Director of STOMP (June 5, 2012).

86. STOMP, *supra* note 84.

87. *Id.*

88. *Id.*

89. *Id.*

make public. Although this Article advocates making such information publicly available in many cases, most parents can currently access it only when they retain a lawyer who has represented numerous families in the same school district, an expense beyond the resources available to many families.⁹⁰

The cost of a facilitated listserv or similar internet-based communication system is not high and can be reduced if a school system successfully applies for a grant from the U.S. Department of Education.⁹¹ In some communities, a non-profit organization may be interested in taking on the responsibility.⁹² Cost issues are more likely to arise if the system succeeds in improving parental competence and conserving parental resources. Parents who feel more competent and have access to more information may become convinced that a school should be providing more resources for their child. In addition, parents might use their new connections to join together to advocate for changes in the system for all children. In recent years, for example, families in the military with children on the autism spectrum have been successful in lobbying Congress to provide their children with more and better services.⁹³ Resources

90. See *infra* note 215; Jeremy Hilton, Navy Veteran, Air Force Spouse, Statement Before the Senate Armed Services Personnel Subcommittee Regarding Military Families Impacted by Disabilities (June 20, 2012), available at <http://www.wrightslaw.com/blog/hilton.sen.test.062012.pdf>.

91. 20 U.S.C. §§ 1470–73 (2006) (authorizing grants for parent information centers); see *Special Education—National Activities—Parent Information Centers*, U.S. DEP’T OF EDUC., <http://www2.ed.gov/programs/oseppic/index.html> (last visited Nov. 22, 2013) (describing grants administered by U.S. Department of Education Office of Special Education Programs for parent information centers such as STOMP); *Parent Center Exchange*, NAT’L PARENT TECHNICAL ASSISTANCE CTR. NETWORK, <http://www.parentcenternetwork.org/national/parentcenterexchange.html> (last visited Nov. 22, 2013) (describing the back-up center funded by the U.S. Department of Education Office of Special Education Programs to support parent information centers). Another example is the New Hampshire Parent Perspectives forum, which has a deliberate focus on parent involvement for the purpose of improving student outcomes. Information can be found at STARTING POINTS FOR NEW HAMPSHIRE PARENTS, http://www.startingpointsforhparents.org/parent_perspectives (last visited Jan. 11, 2014).

92. 20 U.S.C. § 1471(a) (authorizing Secretary to make grants to private non-profit organizations in the community to operate parent information center).

93. See Hilton, *supra* note 90; AUTISM SPEAKS, *ABA Care for Military Kids Clears Senate* (Dec. 5, 2012), <http://www.autismspeaks.org/advocacy/advocacy-news/aba-care-military-kids-clears-senate>; Julian Pecquet, *Military Families Champion Autism Bill*, THE HILL (Jan. 31, 2012); Walter Pincus, *In Times of Tight Budgets, Questions Arise Over What Tricare Should Cover*, WASH. POST, Dec. 14, 2012, at A23. Of course, families also use litigation. See *Berge v. U.S.*, No. 10-cv-00373-RBW (D.D.C. July 26, 2012) (granting plaintiff’s Motion for Summary Judgment and ordering that Department of Defense include ABA therapy in reimbursable expenses under TRICARE Basic Program); P.R. NEWSWIRE, *Military Families File Lawsuit Against Department of Defense for Refusing to Pay for Applied Behavior Analysis Therapy for Children with Autism* (July 6, 2012), <http://www.prnewswire.com/news-releases/military-families-file-lawsuit-against-department-of-defense-for-refusing-to-pay-for-applied-behavior-analysis-therapy-for-children-with-autism-97849624.html> (describing a class action suit by military families seeking Tricare

like the listserv and other internet-based communications are essential to organizing advocacy efforts on that scale, which involve people living all around the world and facing multiple demands on their time, energy, and finances. Even when parents are not geographically separated, internet-based connections can help them get together despite the demands of their special caregiving responsibilities.

B. Commit to Uniform Educational Plans Through a Public Process

While improving inter-parental communication is a good start, parents need more. In particular, parents need a reliable basis on which they can predict what special education services a particular school system is likely to provide for a particular child.⁹⁴ One method for achieving predictability is to require school systems to publicly adopt uniform educational plans for the most common special education situations. Once adopted, the same plan would be provided for every child in the same situation, no less and no more. In the cases of children who have uncommon issues, individualized plans would continue to be developed, as in the current system. Where a child has issues covered by a uniform rule and other issues as well, the uniform plan would be supplemented by an individually developed plan.

In the current system, predictable information is hard for parents to find for two reasons. First, school systems are not required to make public the substance of IEPs; privacy for children and families is the norm.⁹⁵ Second, schools are not required to provide the same IEP to children with the same issues; individualizing the plan for each child is the legal requirement.⁹⁶

Without a doubt, however, many school systems have standardized approaches to educational plans for children with particular issues.⁹⁷ Those plans are well known to school employees with special education responsibilities and to other repeat players, such as

coverage for ABA for child after parent leaves military service); P.R. NEWSWIRE, *Department of Defense and Tri-Care Ordered to Provide Applied Behavioral Therapy to Autistic Children of Military Dependents* (July 26, 2012), <http://www.prnewswire.com/news-releases/department-of-defense-and-tri-care-ordered-to-provide-applied-behavioral-therapy-to-autistic-children-of-military-dependents-163960476.html>.

94. See Pasachoff, *supra* note 1, at 1439–40 (discussing limitations on information available via Parent Information Centers).

95. See *id.* at 1435–37.

96. See *id.* at 1421–24.

97. See, e.g., *Deal v. Hamilton Cnty. Bd. of Educ.*, 392 F.3d 840, 855–59 (6th Cir. 2004); *W.G. v. Bd. of Trs.*, 960 F.2d 1479, 1484–85 (9th Cir. 1992); *Spielberg ex rel. Spielberg v.*

lawyers and experts who represent and work with parents in the same system.⁹⁸ Parents, however, rarely know about the standardized plan.⁹⁹ When school personnel offer the plan to parents in the IEP or IFSP meeting, the plan will be adopted unless the parents make their opposition plain and credible, putting the school personnel on notice that the parents intend to fight for what they think the child needs, and, if need be, to pursue their due process options.¹⁰⁰

A good case can be made for the requirement that each child's educational plan must be crafted for the individual child.¹⁰¹ Requiring individualized attention for each child may deter school personnel from making unwarranted generalizations about the child or applying stereotypes. Individualized planning can also serve to reinforce parental autonomy, which may be key to protecting a child from discrimination.

Despite the law's demand for individuality, however, school systems in practice often try to systematize and routinize special education. School systems are bureaucracies and, like all bureaucracies, they value expertise, uniformity, and internal accountability. Superimposing individuality on a bureaucratic system that provides educational services to thousands of children in classrooms holding tens of children at a time is likely to be difficult.¹⁰² Susie's parents

Henrico County Pub. Sch., 853 F.2d 256, 259 (4th Cir. 1988); *Battle v. Pennsylvania*, 629 F.2d 269, 280–81 (3d Cir. 1980); Hyman, et al., *supra* note 58, at 115.

98. Pasachoff, *supra* note 1, at 1438 (explaining that schools, as repeat players, have greater access to information than a parent whose contact with special education is limited to advocating for own child).

99. *Id.* at 1437 (noting that parents have no right to information about the “universe of services to ask for”); Daniela Caruso, *Bargaining and Distribution in Special Education*, 14 CORNELL J.L. & PUB. POL'Y 171, 187 (2005) (describing how the outcome of IEP negotiations are “kept secret” from other parents).

100. Pasachoff, *supra* note 1, at 1436–37 (stating that lower-resourced parents without adequate information and advocacy assistance are more likely to accept IEP offered by school, even if it is inadequate for child).

101. See Jon Romberg, *The Means Justify the Ends: Structural Due Process in Special Education Law*, 48 HARV. J. ON LEGIS. 415, 454 (2011) (arguing that individualized decisionmaking is more likely to result in a better plan for each child, and, further, that it denies school systems the opportunity to apply presumptions about a child's needs); Engel, *supra* note 4, at 176–77, 185 (arguing that individualized plans are necessary because children differ markedly from one another and schools might otherwise impose preconceptions about a child's capacities); MARTHA MINOW, *MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW* 36–37 (1990) (positing that individualized planning supports parental autonomy); Terry Jean Seligmann, *Sliding Doors: The Rowley Decision, Interpretation of Special Education Law, and What Might Have Been*, 41 J.L. & EDUC. 71, 81–84 (2012) (noting benefits to children of individualized planning); PAUL E. PETERSON, *SAVING SCHOOLS: FROM HORACE MANN TO VIRTUAL LEARNING* 45–46, 49–50 (2010) (arguing that a key contribution of IDEA is giving the claim of parents to education that is customized for their child).

102. See Kirp, Buss, & Kuriloff, *supra* note 2, at 46–47 (documenting conflicts between bureaucratic operation of school systems and individualized claims of students in need of

confronted the tension between individualized planning and bureaucratic response when the case manager said she could only authorize an IFSP composed of ten hours per week of ABA. To go beyond the ten hours each week, Susie's parents would have to initiate a review through the due process system.¹⁰³ From the perspective of the local agency, the values of expertise, uniformity, and internal accountability are all satisfied when the case manager is given limited options. The agency can use its expert personnel to identify an approach that is supported by research or, at a minimum, widely accepted by others in the field.¹⁰⁴ It does not need to rely on the case manager, who may or may not have relevant expertise, to decide which approach is supported by the best studies. The agency can treat almost all families with a child on the autism spectrum the same if they are all offered ten hours per week of ABA, an offer that almost all parents accept.¹⁰⁵ Finally, the agency knows the cost of ten hours per week of ABA for a predictable number of children, so it can plan its budget. Agency personnel can be held accountable for keeping to the budget in all cases other than those involving the rare parents who are able and willing to expend large resources to fight for more services.¹⁰⁶

A systematic, routinized, and bureaucratic response may be entirely appropriate, so long as two conditions are met. First, the response must be one that is created through a transparent process, so that parents and other interested members of the public are aware of the policies and have an opportunity for input. Second, the process for deciding that a particular approach is proper for a

special education); Caruso, *supra* note 99, at 196 (noting that uniformity is valued by bureaucratic systems such as schools).

103. See *supra* note 58–59.

104. The U.S. Department of Education operates a project called What Works Clearinghouse tasked with reviewing research on approaches to special education for the purpose of identifying studies with the highest degree of reliability. For more information, see INST. OF EDUC. SCIS., <http://ies.ed.gov/ncee/wwc/> (last visited Nov. 22, 2013).

105. See Bitterman et al., *supra* note 22, at 1513.

106. While special education is generally quite expensive, the costs are unusually high for children on the autism spectrum. See Weber, *supra* note 10, at 50–52 (recommending additional federal funding for students on the spectrum). The individualized due process approach of the IDEA deprives the school system of a degree of budgetary control because hearing officers and courts are not in a position to decide whether expenditures made for a particular child are justifiable in light of the school system's overall budget. Neal & Kirp, *supra* note 2, at 84; Erin Phillips, *When Parents Aren't Enough: External Advocacy in Special Education*, 117 YALE L.J. 1802, 1826 (2008) (noting the unpredictability of special education costs because of individualized plans). Further, most courts have held that the cost of providing particular services is not a relevant consideration under IDEA except in narrow circumstances. See *Mills v. Bd. of Ed.*, 348 F. Supp. 866, 876 (D.D.C. 1972) (finding that the cost of services is not a permissible consideration).

particular child must be careful so that it is used only for children who may benefit educationally.

The upsides of allowing a bureaucratic response are many.¹⁰⁷ First, bureaucratic systems rely on expertise, so it may be more likely that decisions about which special education services to offer will be based on research and evidence rather than on a gut-level feeling about what should work.¹⁰⁸ Second, bureaucratic systems rely on uniformity, so children who are similar usually will be treated similarly, regardless of what resources their parents can bring to bear on the decision.¹⁰⁹ Third, bureaucratic systems value internal accountability, so a bureaucratic response may involve an insistence on including the appropriate complement of pertinent services in each IEP.¹¹⁰

There are two large caveats to this conclusion, however. The first one has to do with reliability. If a system is going to treat similar children the same, it is essential that evaluations of those children be reliable and untainted by the self-interest of the school system or the differences among parents.¹¹¹ It would be tempting for schools to identify children as belonging in a category that requires more or less expensive educational interventions, but allowing that to happen undermines the credibility of the entire system.

107. See Neal & Kirp, *supra* note 2, at 84–86 (arguing that an individualized due process approach may undermine the importance of expertise of teachers and the financial accountability of school systems, which may diminish benefits of IDEA for children in need of services).

108. See Sarah D. Sparks, 'What Works' Broadens Its Research Standards: Clearinghouse Moves Past 'Gold Standard', 30 EDUC. WK. 1 (Oct. 20, 2010), <http://www.edweek.org/ew/articles/2010/10/20/08wwc.h30.html?tkn=VONFXdkDm9RUdDyWUzY5E2nInbitQAuv3nl0&cmp=clp-edweek> (describing how creation of federal office tasked with evaluating studies on educational research intended to help school administrators identify those with adequate evidence and use that evidence to evaluate proposed educational plans and practices).

109. Uniformity also permits school systems to monitor whether children in need of services are being treated equivalently, at least in terms of the expense to the school system. See *Renner v. Bd. of Educ.*, 185 F.3d 635, 646 (6th Cir. 1999) (determining that cost is permissible consideration for school district in pursuit of goal of treating children equally).

110. See Phillips, *supra* note 106, at 1830–32 (explaining that many parents are unaware of the educational options appropriate and available for their child). Accountability can and should take place at many levels, beginning internally and extending through reviewing entities at the local, state, and national levels. See generally Pasachoff, *supra* note 1, at 1473–84.

111. See Hyman, et al., *supra* note 58, at 115; ONG-DEAN, *supra* note 4, at 63–93 (identifying student's condition is not simple and can be affected by whether parents are endowed with cultural and economic capital); William Dikel and Daniel Stewart, *Emotional/Behavioral Disorders and Special Education: Recommendations for System Redesign of a Failed Category*, 34 *HAMILINE L. REV.* 589 (2011) (identifying emotional disorder as a good example of difficulties of diagnosis); Ruth Colker, *The Learning Disability Mess*, 20 *AM. U. J. GENDER SOC. POL'Y & L.* 81 (2011) (giving learning disabilities as another example of the difficulties of diagnosis); James E. Ryan, *Poverty as Disability and the Future of Special Education Law* (Univ. of Va. Sch. of Law Pub. Law & Legal Theory, Research Paper Series No. 2012-63, 2012), available at <http://ssrn.com/abstract=2152557> (noting the impact of poverty on diagnoses of learning disability).

The second has to do with accountability. At present, schools do not need to disclose to the public which educational plans they deem appropriate for students with particular issues.¹¹² Accountability is accorded little value in comparison with privacy. That is, the individualized system is kept private in order to protect the privacy of each child and family from the disclosure of information about what may be seen as a stigmatized condition.¹¹³ The privacy rationale is irrelevant, however, when a school system is in the process of deciding which educational plan is appropriate for all children with the same issue. There is no privacy interest involved in allowing the public access to what the school system thinks are the appropriate services, and the public should be given a chance to influence this decision.¹¹⁴ Parents can elect whether to engage in the review process, so those who value privacy can remain silent or support others to speak in their stead.

This procedure might appropriately be analogized to rulemaking, the process through which administrative agencies are authorized to make rules applicable to members of the public.¹¹⁵ In effect, administrative agencies engaged in rulemaking are performing legislative acts even though they are not legislative bodies. The action is justified and allowed to constitute binding law only if the

112. The norm of individualized planning for each child impedes accountability in litigation as well, since parents cannot use the existence of a rule to challenge administratively a practice that is affecting multiple children. See ONG-DEAN, *supra* note 4, at 35. Compare *Armstrong v. Kline*, 476 F. Supp. 583, 602–05 (E.D. Pa. 1979) with *Hoeft v. Tucson Unified Sch. Dist.*, 967 F.2d 1298, 1303–05 (1992).

113. See ONG-DEAN, *supra* note 4, at 13.

114. Other benefits may flow from greater disclosure of information about substantive provisions of IEPs, including greater equity across jurisdictions. See Pasachoff, *supra* note 1, at 1466–71. At the same time, many of the children who are eligible for IEPs have problems that are not common to large groups of children. Public rulemaking or standard-setting is not useful for them because the rule or standard, once adopted, will not apply in enough cases. Parents still need information about what kinds of approaches are likely to be offered by the school system, however. A useful intermediate approach that still respects the needs of some parents and children for privacy would be an annual report listing the IEPs adopted for different groups of children without identifying the particular children. Where a hearing has been held, the hearing officer could be required to publish a version of the decision that discloses the services provided under the IEP without revealing the identity of the child. See Kirp, Buss & Kuriloff, *supra* note 2, at 148; ONG-DEAN, *supra* note 4, at 25 (comparing vision of Kirp, Buss and Kuriloff about due process hearings promoting change throughout special education system to current reality of due process hearings focused solely on individualized plan for single child).

115. Cf. Kirp, Buss & Kuriloff, *supra* note 2, at 154 (proposing rulemaking in limited arenas affecting procedures of special education cases).

public has advance notice of the rule and an opportunity to be heard as to whether it should be adopted, modified, or rejected.¹¹⁶

School systems, like most local agencies, are not subject to state administrative procedure laws requiring rulemaking.¹¹⁷ School boards are usually politically accountable, however, much like legislatures.¹¹⁸ As a result, many decisions about general education are made through public votes by the school board after debate and consideration in public meetings.¹¹⁹ One way to ensure that special education is given a similar level of visibility and political accountability would be to have its standard practices subject to the same public votes after public consideration.

A better solution would be to require an informal rulemaking or standard-setting process under which the school system announces its plans for particular types of special education, explains those plans, and justifies them. This process would give the public an opportunity to learn about, respond to, and potentially amend the plan before it is adopted.¹²⁰

If adopted, a rulemaking or standard-setting process would eliminate the need to individualize educational plans with respect to special education needs that many children share. In other words, where a child's issues are covered by a rule or standard, only those services identified in the rule or standard would be provided. Since

116. See Hyman, et al., *supra* note 58, at 151–52 (describing and advocating for use of analogous administrative review procedures to achieve substantive improvements in the services offered by a school system). See generally KENNETH CULP DAVIS, *DISCRETIONARY JUSTICE* (La. State Univ. Press, 1969).

117. See generally Ronald M. Levin, *Rulemaking Under the 2010 Model State Administrative Procedure Act*, 20 WIDENER L.J. 855 (2011); REVISED MODEL STATE ADMIN. PROCEDURE ACT § 102(3) (2010), available at http://www.uniformlaws.org/shared/docs/state%20administrative%20procedure/msapa_final_10.pdf (defining “agency” at state level).

118. See *Page v. Lexington Cnty. Sch. Dist. One*, 531 F.3d 275, 287 (2008) (finding that school boards are elected and, therefore, that voters can express their disagreement with a school board decision at the ballot box).

119. See generally Robert A. Garda, Jr. & David S. Doty, *The Legal Impact of Emerging Governance Models on Public Education and Its Office Holders*, 45 URB. LAW. 21 (2013).

120. If state APAs were applicable to local agencies, then the Model Act would provide for two kinds of standard-setting: adoption of a rule and adoption of a guidance document. Each provides for public knowledge about the standard and for public input into its content, but to quite different degrees. Guidance documents can be adopted with less prescreening, and they are subject to fewer requirements with respect to public input and maintaining the record. See generally Levin, *supra* note 117. For the purposes of special education reform, guidance documents could be helpful to parents because they will make public the content of IEPs that will usually be offered in particular situations. Also, because guidance documents can be binding on agency personnel, they will usually satisfy the interests of school systems in accountability of personnel. However, there are fairness concerns if those affected by a policy have no opportunity to be heard on its content, especially where agency personnel consider themselves bound. Further, if a person can avoid the imposition of the policy only through litigation, horizontal equity problems continue. See generally Nina A. Mendelson, *Regulatory Beneficiaries and Informal Agency Policymaking*, 92 CORNELL L. REV. 397 (2007).

education is a dynamic field, no rule or standard should be assumed to be permanent. Instead, periodic review should be part of the system, including regularly scheduled opportunities for educators, parents, and scholars to consider whether a new rule or standard is advisable.

Some parents would experience uniform plans as a loss, particularly in terms of autonomy. For example, under current law, parents have the right to participate in the formulation of an IEP.¹²¹ As reformed, many plans would be predetermined and parental participation would not be required once the child's issues were identified.¹²²

As a practical matter, however, predetermination may be the norm, even now, for most children.¹²³ In addition to the bureaucratic goals explained earlier, predetermination may be less objectionable now than at the birth of the IDEA for at least two reasons. First, after forty years of experience, school systems probably have enough data to identify which services will be adequate for most children and can be provided at a reasonable cost. For example, a national survey of preschool children with autism found that nearly ninety percent of the children received speech therapy, over two-thirds received occupational therapy, and nearly half received behavior management services.¹²⁴ Second, most parents do not have the inclination or the resources to demand something different from the usual plan.¹²⁵ Many parents in the same national survey reported some level of dissatisfaction with the number or frequency of services specified in their child's IEP, but their dissatisfaction did not appear to result in changes to IEPs.¹²⁶ That is not surprising, since few parents take advantage of procedures available

121. See *supra* note 58.

122. See *Knable v. Bexley City Sch. Dist.*, 238 F.3d 755, 765 (6th Cir. 2001) (deciding that predetermination violates parental right to participate in formulating IEP); Dicker & Bennett, *supra* note 48, at 427–29; *supra* note 36.

123. See Seligmann, *supra* note 101, at 86 (acknowledging that, despite legal requirements, “cookie-cutter” plans are probably the norm in many districts); BARBARA D. BATEMAN & MARY ANNE LINDEN, *BETTER IEPs; HOW TO DEVELOP LEGALLY CORRECT AND EDUCATIONALLY USEFUL PROGRAMS* 109–13 (4th ed. 2006) (concluding that certain IEPs are written in a way that “[does] not in any way include looking at the individual student”).

124. See Bitterman et al., *supra* note 22, at 1513.

125. See Engel, *supra* note 4, at 188–89 (providing parents' descriptions of themselves in IEP meetings as “terrified and inarticulate”; they do not see their understanding of the child as being credited by the decisionmakers); Schaffer *ex rel.* Schaffer v. Weast, 546 U.S. 49, 66–67 (2005) (Ginsburg, J., dissenting) (explaining that the “vast majority” of parents do not challenge the IEP proposed by the school system).

126. *Schaffer*, 546 U.S. at 66–67 (Ginsburg, J., dissenting).

to them under the IDEA to contest the school system's proposal for the child's IEP.¹²⁷

Even if eliminating individualization in educational plans were a major change from current practice, the reform is justifiable because it would improve horizontal equity among children in need of special education.¹²⁸ Present IEP variations exist because some parents have the resources to dispute the proposed IEP while others do not. Some parents may be able to obtain more services or more frequent delivery of services than other parents. If services are prescribed by a rule or a standard, on the other hand, all children with the same needs will be treated the same. It may turn out that some children will receive a lower level of service than under the current system, but, in general, this will be true only for a relatively small group of privileged children. For other children, the rule-based services may be more suitable or greater in number, frequency, or duration than what would be provided now.

The proposed reform is also beneficial because it supports parental competence and conserving parental resources. With respect to supporting parental competence, a public informal rulemaking or standard-setting process can improve the confidence that parents have about a proposed approach for helping their child. The process affords parents access to more information about the school system's approach to a child's issues and why the school system believes the approach is supported by research and experience. Where parents remain unconvinced, they do not have to fight individually for change; they can join with others to demand improvements. For example, a New York county once refused to provide ABA therapy as an intervention service.¹²⁹ It was only after one child's parents paid for the therapy privately and sued for reimbursement that it was revealed that the county's decision not to provide ABA or any comparable alternative was made pursuant to a county policy in all cases involving young children with autism.¹³⁰ The policy, once revealed in the litigation, was indefensible, and changes were implemented statewide.¹³¹ Had the policy been announced as a proposed rule or standard, parents of children on the

127. See Bagenstos, *supra* note 58; Mark A. Mlawer, *Who Should Fight?: Parents and the Advocacy Expectation*, 4 J. DISABILITY. POL'Y STUDIES 105, 108–09 (1993).

128. See *infra* notes 212–22.

129. See generally *Malkentzos v. DeBuono*, 923 F. Supp. 505 (S.D.N.Y. 1996), *vacated on other grounds*, 102 F.3d 50 (2d. Cir. 1996). Another New York county was successfully sued by a group of children and parents because ABA was provided for children eligible for early intervention, but services were generally limited to ten hours per week pursuant to a policy that had never been made public. *BD v. DeBuono*, 130 F. Supp. 2d 401 (S.D.N.Y. 2000).

130. *DeBuono*, 130 F. Supp. 2d 401.

131. See *Womack*, *supra* note 16, at 231–32.

autism spectrum could have joined together to persuade the county to reject the proposal. The parents who litigated the case could have been spared the financial, social, and emotional costs of litigating against the school system.¹³²

Parents with special needs children, as well as parents with children in general education, have expressed dissatisfaction with the role that cost plays in IEP determinations. Not unreasonably, some parents seeking special education services suspect that what a school proposes for a child's IEP is inappropriately determined by the cost of the services and suspect that more services would be provided if cost were no issue.¹³³ At the same time, some parents whose children are in general education object to the school spending large sums for special education to the possible detriment of spending on general education.¹³⁴ Requiring the school system to subject its plans to public review would give an opportunity for both groups of parents to be heard and for both to advocate for a spending level that they deem appropriate.¹³⁵

A public process would also create a forum for addressing substantive questions about the appropriateness of different kinds of educational interventions. The process would give parents the opportunity to learn more about possible educational practices outside of the pressure cooker environment of making a specific decision for their specific child. Advocates for autistic children and adults have criticized interventions that, in their view, seek to eliminate autism rather than accepting the child for who the child is.¹³⁶

132. See Glennon, *supra* note 4, at 354 (arguing that individual remedy structure of IDEA fails to address systemic problems that keep schools from educating students with emotional disabilities). Over a period of time, however, litigation may produce some changes in the school system that benefit children other than those whose parents litigate. See Janet R. Decker, *A Comprehensive Analysis of Applied Behavior Analysis (ABA) Litigation Trends for Students with Autism*, 274 ED. L. REP. 1, 20–21 (2012) (noting that ABA litigation may have produced changes in willingness of school systems to provide the service, and, further, that the focus of more recent litigation has often been on the number of hours of ABA rather than on availability of therapy).

133. Caruso, *supra* note 99.

134. See *id.* at 191–92. See generally Elizabeth Burleson, *Perspective on Economic Critiques of Disability Law: The Multifaceted Federal Role in Balancing Equity and Efficiency*, 8 IND. HEALTH L. REV. 337, 347–53 (2011).

135. Consideration of cost is not prohibited under the IDEA in some circumstances. See *Renner v. Bd. of Educ.*, 185 F.3d 635 (6th Cir. 1999) (quoting *Nelson v. Southfield Pub. Sch.*, 384 N.W.2d 423 (1986)) (stating that, at least where two alternative treatments provide an approximately equivalent level of benefit, relative cost can be considered). Cf. Karen Czapan-skiy & Rashida Manjoo, *The Right of Public Participation in the Law-Making Process and the Role of the Legislature in the Promotion of this Right*, 19 DUKE J. COMP. & INT'L L. 1, 15 (2008) (explaining the importance to democratic process for controversial issues to be surfaced and subjected to public discussion and debate).

136. See *id.* at 275–80.

For example, some people have criticized educational plans that give priority to the development of language and social skills as evidence of parental rejection of the autistic child.¹³⁷ Behavioral therapies, such as ABA, also fall into this category. According to these advocates, an example of acceptance could mean educational plans focused on skills that the child finds more compatible with his or her autistic characteristics, such as math, spacial relationships, and the study of animal behavior.¹³⁸ The school's disclosures and justifications and the public discussion may reduce the occasions for parents to doubt whether the services identified in their child's IEP are supported by good research and sound policy.

The disclosures should also give parents a basis for developing realistic expectations about what the school can and cannot do for a child. Both Charlie's parents and Susie's parents, for example, developed confidence that ABA was a productive approach for their children because they saw how it worked. Yet their individual experiences can only take their confidence levels so far; experience provides no information, for example, on whether improvements in the child's condition will last or whether other approaches might have produced even greater short-term or long-term gains. In a public process where ABA is proposed, explained, and justified by experts from the school system, parents would be given an opportunity to learn enough to determine whether their confidence is justified.

The role of advocacy in public rulemaking or standard-setting process could serve the goals of supporting parental competence and conserving parental resources. Such a process only works if people in the public respond to what is being proposed by the school system. Responding would mean making one's views known, so parents participating in the process have to learn enough about the proposal to develop a point of view and express it to decision-makers. This would be a time-consuming and difficult process, but the competence the parent develops in the course of the advocacy effort could then be taken into the process of advocating for the child in IEP meetings.

At the same time, advocacy usually works best when it is undertaken with others. A public rulemaking process gives each parent the chance to meet and join with other parents who want the same or similar outcomes. Allied parents can also support each other

137. *See id.* at 276, 279.

138. *See id.* at 273–74. *See generally* Kevin Barry, *Gray Matters: Autism, Impairment, and the End of Binaries*, 49 SAN DIEGO L. REV. 161 (2012).

when confronting arguments raised by people who disagree with them.¹³⁹

In the case of rulemaking around IEPs, the advocacy process offers another benefit: incentives for parents who are quite different in terms of personal resources to join together as advocates. The reason is straightforward. Today, higher-resourced parents can use their time, energy, and money to fight a school system and get a “gold standard” IEP for their child. If the IEP for many children is not individualized but instead based on a rule or a standard, then these parents would not be able to get a different plan for their child no matter how much they paid lawyers or experts to help them advocate. Their only way to get the kind of plan they think desirable for their child would be to help all children have access to the same plan under the school board’s rule or standard.

Where parents across the resource spectrum have an incentive to work together, all stand to benefit to some degree.¹⁴⁰ The benefit to higher-resourced parents is that they may gain support from parents with fewer resources, so long as they all join together to advocate for the same rule or standard. The benefit to the lower-resourced parents is that they can use the expertise developed by higher-resourced parents without having to spend time doing additional research or investigation. They may also benefit from observing advocacy skills employed by people who are more likely to expect success in their interactions with bureaucracies. Both groups can conserve resources by working in concert. They may also attract community groups to enhance their efforts, which may amplify their impact without exhausting their individual resources.¹⁴¹

A rulemaking or standard-setting process is also likely to conserve parental resources by making the outcome of the IEP more predictable. At present, a parent has no easy way to predict what a school will propose for their child’s IEP or IFSP. A more predictable system would allow parents to save resources now expended on

139. The most likely source of disagreement is around cost, since special education is an expensive enterprise for local school systems. *See supra* note 106. An important benefit of the rulemaking process is that the cost issues can be debated publicly rather than, as is now the case, submerged into the decision-making affecting individual students, usually to the detriment of students whose parents have the fewest resources.

140. *See Engel, supra* note 4, at 196–99 (noting that one possible cost of individualization of IEP system is that parents and children may be deprived of seeing themselves as part of the community).

141. *See Kirp, Buss & Kuriloff, supra* note 2, at 126–29 (suggesting allowing advocacy organizations and governmental oversight agency to participate in IEP process because of need to be proactive and critical about creating special education resources as well as using existing resources).

researching and creating plans, litigating disagreements, and remaining in jurisdictions unlikely to provide desired services to their children.

For example, many conscientious parents try to come up with their own plan, a process that can require the investment of substantial resources for research and investigation. If Susie's parents had spent their resources that way before the local agency proposed its IFSP, it would have been a waste of time. Clearly, the jurisdiction was not going to propose anything other than ten hours of ABA. Unfortunately, that information was not available publically, so Susie's parents could not predict what the proposed IFSP would be. Under a public rulemaking or standard-setting process, on the other hand, Susie's parents would know that the jurisdiction, after undertaking the necessary rulemaking process, had concluded that the most effective therapy it could offer children on the autism spectrum was ten hours a week of ABA. Susie's parents would be unlikely to prevail if they appealed from that decision, so they would probably decide not to expend time and resources on pursuing either the research into alternative therapies or an appeal from the proposed IFSP.

Similarly, many parents report that pursuing their legal rights is a fraught experience that exhausts them emotionally and consumes time and money.¹⁴² Instead, under a predictable system, parents like Susie's could expend time and energy getting as much as they could out of their child's ten hours of weekly ABA rather than expending unnecessary resources on pursuing legal rights. They might also use their enhanced access to information to use their resources to join with other parents to seek a change in the rule or standard.

Finally, under a more predictable procedure, Susie's parents would know early in the process to investigate whether Susie's preschool IEP was likely to be the same as or different from her IFSP. Because the information would be public, they might, as some military families do, take advantage of their knowledge to decide to move somewhere else before Susie turns three.

142. See Neal & Kirp, *supra* note 2, at 79 (considering parental reports about negative consequences of exercising due process rights under IDEA).

*C. Adopt Universal Design Options in General Education
When Practicable*

The most expensive of the changes that would support parental competence and conserve parental resources is the adoption of universal design pedagogic approaches. Universal design approaches require changes to the general educational environment in ways that permit people with disabilities to be included without special treatment. In other words, some children who need access to special educational services would not need those services or would need fewer of them if the general educational system were modified to meet the needs of more students. When the general education system becomes adequate, parents do not need to develop special competencies to help their children, nor do they need to expend resources to advocate for their children.

The term “universal design pedagogic approaches” echoes the more familiar idea of universal design of physical spaces.¹⁴³ Where universal design is the goal, buildings and physical spaces are created in ways that make them accessible to all people, including those with disabilities. Probably the most familiar example is the ramp that replaces or supplements the staircase.

Largely because of legal requirements, universal design of public spaces is routine.¹⁴⁴ As a result, school buildings, like other public buildings, are constructed or retrofitted with grab rails and ramps.¹⁴⁵ Where universal design of schools has been accomplished, parents no longer have to struggle just to get their child into a school building. As important as universal design is to people with disabilities, it often turns out to offer unexpected benefits to groups of people who are not targeted by the change. Curb cuts and ramps, for example, ease mobility for people in wheelchairs.¹⁴⁶ They also turn out to be helpful to people travelling with strollers, wheeled suitcases, and shopping carts.¹⁴⁷

143. See Martha Minow, *Universal Design in Education: Remaking All the Difference*, in *RIGHTING EDUCATIONAL WRONGS*, 38, 53–57 (Arlene S. Kanter & Beth A. Ferri eds. 2013) 53–57 (explaining the application of universal design inclusionary principles in education and exploring the example of universal design standards for textbooks); Michael Ashley Stein, *Same Struggle, Different Difference: ADA Accommodations as Antidiscrimination*, 153 U. PA. L. REV. 579, 640–45 (2004) (explaining concept of universal design in physical environment); Polly Welch, *What is Universal Design?*, in *STRATEGIES FOR TEACHING UNIVERSAL DESIGN I* (Polly Welch ed., 1995), available at <http://www.udeducation.org/resources/62.html> (introducing the theory and history of universal design as applied to built environment).

144. Welch, *supra* note 143.

145. *Id.*

146. *Id.*

147. See Martha Minow, Response, *Accommodating Integration*, 157 U. PA. L. REV. ONLINE 1, 2 (2008), available at <http://www.pennumbra.com/responses/10-2008/Minow.pdf> (citing

Pedagogic approaches can also exhibit universal design characteristics that work both to include children with disabilities and to expand possibilities for children who do not have disabilities.¹⁴⁸ For example, Charlie's kindergarten class was in a school that uses Response to Intervention, or RTI, a universal design pedagogic approach under which all students are treated as if they may need additional help.¹⁴⁹ RTI uses processes to identify which students are in need of help at an early stage and provides those students with additional resources before they fall behind.¹⁵⁰ Under RTI, Charlie was initially treated just like his classmates. Once Charlie and some others demonstrated through testing that they were not mastering the material, additional resources were added. The same system was applied to all the students at routine intervals, and each student's results determined what educational approach and resources would be used next.¹⁵¹

RTI is not a substitute for special education. It may, however, result in some students not moving into special education at an early stage.¹⁵² Since each child's progress is measured against the same standard, each child can be helped in ways appropriate to that child. Some children may receive help that they would have received under an IEP, but neither the school nor the parents have to spend time, energy, or resources establishing the IEP before the child begins to get help. RTI does not eliminate IEPs for children who need them, but it can make it possible for children to receive

curb cut as one of many examples of universal design that allow access by disabled people and simultaneously provide benefits to people not identified as disabled).

148. See Elizabeth F. Emens, *Integrating Accommodation*, 156 U. PA. L. REV. 839, 855–57 (2008) (stating that universal instructional design imports into education the principles of universal design as applied to physical spaces and products).

149. See Rollanda E. O'Connor & Victoria Sanchez, *Responsiveness to Intervention Models for Reducing Reading Difficulties and Identifying Learning Disabilities*, in HANDBOOK OF SPECIAL EDUCATION 23 (James M. Kauffman & Daniel P. Hallahan eds., 2011) (providing an in-depth examination of strengths and weaknesses in evidence about RTI); Angela A. Ciolfi & James E. Ryan, *Race and Response-To-Intervention in Special Education*, 54 HOW. L.J. 303, 305–10 (2011) (describing RTI and 2004 amendments to IDEA allowing school systems to use RTI as diagnostic tool and to use portion of IDEA funding stream for RTI); Weber, *supra* note 10, at 21–23 (2006) (discussing concerns about allowing schools to divert funding for special education into early intervention programs such as RTI).

150. See Ciolfi & Ryan, *supra* note 149, at 310–13 (explaining history and characteristics of RTI).

151. Ryan, *supra* note 111.

152. See Ciolfi & Ryan, *supra* note 149, at 318 (explaining complications hindering ability to correctly distinguish amongst students).

targeted help, regardless of whether an IEP has already been established.¹⁵³

Another example of a universal design pedagogic approach is mandating that teachers post homework assignments on a school website that is accessible to parents.¹⁵⁴ Communicating assignments to parents is a common feature of IEPs for children with Attention Deficit-Hyperactivity Disorder (ADHD).¹⁵⁵ Often parents try to monitor whether their child is doing required homework because, otherwise, the child might get distracted and not complete assignments.¹⁵⁶ Typically, however, people with ADHD are also more likely to forget assignments or fail to make adequate notes about them, with the result that IEPs often place the responsibility on teachers to communicate assignments to parents.¹⁵⁷ Where a school has the capacity to communicate with all parents simultaneously, however, the teacher can post everything in one location, and all parents can use that location to learn about assignments.¹⁵⁸ The system helps students with ADHD and parents who support them. It also helps other students, including those who missed school due to illness or who were in class but did not fully understand what the teacher expected when the assignment was announced.

153. Memorandum from Melody Musgrove, Dir. of Office of Special Educ., U.S. Dep't. of Educ. to State Dirs. of Special Educ. (Jan. 21, 2011) (explaining evaluation of student suspected of having a disability not to be delayed by student's participation in RTI). *But see* Ciolfi & Ryan, *supra* note 149, at 315–17 (explaining the relationship between RTI and IDEA still murky and referral for IEP may be delayed for student in RTI classrooms); Colker, *supra* note 111, at 92–96 (criticizing RTI as diagnostic substitute for identifying students with learning disabilities).

154. This approach works best, of course, where all parents have access to the internet, something not yet achieved in many neighborhoods housing families with fewer resources.

155. My description of the educational concerns of parents with a child with ADHD is based heavily on my own experiences as the parent of a child diagnosed in middle school with ADHD. Experts in the field see many students, teachers, and parents having similar experiences, and they draw similar conclusions. *See* CHRIS A. ZEIGLER DENDY, ADHD, EXECUTIVE FUNCTION AND SCHOOL SUCCESS, ADD RES. CTR. (2011), available at <http://www.addrc.org/executive-function-and-school-success/>; Russell A. Barkley, *80+ Classroom Accommodations for Children or Teens with ADHD*, 16 THE ADHD REPORT 7 (2008).

156. Barkley, *supra* note 155.

157. *See, e.g.*, S. v. Wissahickon Sch. Dist., No. 05-1284, 2008 WL 2876567, at *7 (E.D. Pa. July 24, 2008). *See generally* THOMAS J. POWER ET AL., HOMEWORK SUCCESS FOR CHILDREN WITH ADHD 5–8 (2001); Joshua M. Langberg et al., *Materials Organization, Planning, and Homework Completion in Middle-School Students with ADHD: Impact on Academic Performance*, 3 SCH. MENTAL HEALTH 93 (2011); EDWARD M. HALLOWELL & JOHN J. RATEY, DRIVEN TO DISTRACTION 41–69 (1994).

158. Fortunately for my child, my spouse, and me, my child's high school had the capacity to communicate assignments via the internet. Teachers who regularly used the system made homework monitoring possible, and over the four years of high school, my child could take increasing responsibility for homework—a skill that was essential for his later success in college. During middle school, however, no regular system was in place for notifying me or any other parent about assignments, and my child had a terrible time.

For some students with ADHD, an IEP is not necessary so long as parents have sufficient information to help their child with school work, or at least monitor the child's performance. Universal posting of assignments may provide enough information. In those circumstances, just as with RTI in some cases, neither the school nor the parent has to expend resources deciding whether the child is eligible for an IEP, determining what the IEP should cover, or monitoring the school's conduct under the IEP.

In terms of supporting parental competence, universal design of pedagogic approaches is an important complement to special education because it adds benefits that cannot be achieved in a system organized exclusively around individualized educational plans. While many IEPs can and should result in children being mainstreamed in general education classrooms,¹⁵⁹ the absence of universal design probably means that more children cannot be mainstreamed because of their individual needs or because of their impact on other children.¹⁶⁰ When more special education and general education students share the same classroom, parents of children with IEPs have opportunities to develop relationships with parents of children in general education and learn what opportunities may exist for their children in general education settings. Their enhanced competencies can translate into better parenting.

The impact of universal design on resource conservation is more obvious. If RTI or a similar pedagogic approach can reduce or delay the need for special education, parents do not have to spend time, energy, or money seeking an assessment of their child, developing an IEP with the school system, or monitoring the IEP. Those resources can then be much better spent caring for the child, earning a living, or taking care of the parent's physical and emotional needs. Further, under RTI, children are routinely identified as needing more or less help, and the school system takes the first line of responsibility for identifying and providing the necessary help. Parents whose children are identified can join together to work with the school system to provide help regardless of whether the children differ from one another in terms of a specific learning problem or IEP. They do not need to compete with each other for the scarce resources that might be made available otherwise only to the children of highly-resourced parents.

159. See ROTHSTEIN & IRZYK, *supra* note 3, at § 2:18.

160. See Roberts, *supra* note 24 (discussing generally the problems with mainstreaming students with disabilities).

V. HOW CAN THE EFFORT OF MAKING PARENT-ORIENTED REFORMS BE JUSTIFIED?

The changes suggested here may make sense, and they may even be convincing as a way to improve the quality of the lives of parents of special needs children, but they beg an essential question: why should the special education system, a system designed to provide educational opportunities to previously excluded children, be changed to make it more accessible to parents? Although parents may be viewed as mediators for the child's experiences in the world, including in education, effective policies directed at including parents and respecting their roles have been inconsistent at best and nonexistent at worst. Reasons to pursue policies and practices that address the needs of parents within the scope of special education programs fall into four categories: congressional mandate, pragmatism, social justice for parents whose children have special needs, and fairness among those parents.

A. *Congressional Mandate*

In the case of *Winkelman v. Parma City School District*, the Supreme Court stated that, because parents have an independent stake in the education of their children under IDEA, parents also have standing to sue on their own behalf under the IDEA.¹⁶¹ According to the Court:

[The] IDEA, through its text and structure, creates in parents an independent stake not only in the procedures and costs implicated by this process but also in the substantive decisions to be made . . . Parents may seek to enforce this mandate through the federal courts, we conclude, because among the rights they enjoy is the right to a free appropriate public education for their child.¹⁶²

161. 550 U.S. 516, 526–33 (1994).

162. *Id.* at 531–32; see Martha C. Nussbaum, *Foreword: Constitutions and Capabilities: "Perception" Against Lofty Formalism*, 121 HARV. L. REV. 4 (2007); Robin West, *Human Capabilities and Human Authorities: A Comment on Martha Nussbaum's Women and Human Development*, 15 ST. THOMAS L. REV. 757, 774–78 (2003) (arguing that constitutional claims may also support parental right, particularly when the capability for human relationships includes capability to be a parent).

In other words, Congress included parents, as well as children, within the groups of people who have rights under the IDEA.¹⁶³ Beginning as early as 1975, Congress made an “effort to maximize parental involvement in the education of each handicapped child” through, among other things, requiring states to include parents in meetings about the design and implementation of the IEP, ensuring that parents have access to records and expertise, and providing opportunities to contest a school’s plans for the child.¹⁶⁴ As a practical matter, achieving this congressional goal increases in difficulty when the school system adopts practices that give short shrift to parental interests in competence and conservation of resources.

With respect to infants and toddlers, Congress was more explicit about a focus on the family. In 1986, Congress amended IDEA to add Part C, the Infants and Toddlers with Disabilities Program.¹⁶⁵ Under Part B of the IDEA, which was at issue in *Winkelman* and is applicable to pre-school children and school-age students, the educational plan for a child who qualifies for services is called an “Individual Education Program.”¹⁶⁶ Consistent with its name, the plan is developed in response to an evaluation of the child’s individual needs, and the family is not an explicit focus of services.¹⁶⁷ Part C, which is applicable to infants and toddlers, focuses on the child in the context of the child’s family. Services are provided under the terms of an “individualized family service plan,” which must include “a statement of the measurable results or outcomes expected to be achieved for the infant or toddler AND the family.”¹⁶⁸ The assessment process must include “a family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family’s capacity to meet the developmental needs of the infant or toddler.”¹⁶⁹

Congressional attentiveness to parents reflected concerns about the stigma that could attach to special needs children. Parental involvement can not only reduce stigmatization, however; it can also

163. See *Recommended Outcomes*, *supra* note 61, at 229–30 (discussing the congressional intent to include families as target of services under Part C and, by clear implication, under Part B); Phillips, *supra* note 106, at 1814–15 (explaining that congressional decision to include parents is understandable because of widespread assumption that parents are best advocates for their children).

164. See *Bd. of Educ. v. Rowley*, 458 U.S. 176, 183, n.6 (1982).

165. 20 U.S.C. § 1400 *et seq.* (2006).

166. 20 U.S.C. § 1412(a)(3)–(4) (2006).

167. See 20 U.S.C. § 1414(c)(1) (2006).

168. 20 U.S.C. § 1436(d)(3) (2006) (emphasis added); 20 U.S.C. § 1412(a)(3) (2006).

169. 20 U.S.C. § 1436(a)(2) (2006); 20 U.S.C. § 1412(a)(3) (2006).

give parents the chance to push the school system toward responding to the child in ways calculated to help the child succeed. The congressional mandate, then, also has its pragmatic side.

B. Pragmatism

From the perspective of pragmatism, the question of whether parents should be part of the focus of special education policy turns on what works best for the child or student. For decades, people studying children and families have hypothesized that, when the parent is involved and capable of contributing to the child's learning and development, the child usually does better educationally as well as developmentally.¹⁷⁰ Determining how and why this happens has been more elusive,¹⁷¹ but the theory remains unshaken.

Success can be measured in many ways, including academic achievement, social skills, and emotional development.¹⁷² Regardless of the objective, studies often find that parental involvement improves the likelihood of the child's success.¹⁷³ Like many aspects of parenting, parental involvement may be more important when the child is young than when the child grows older. The degree of impact may also turn on the level of maturity and education that the parent brings to the effort. The basic lesson remains, however,

170. See generally URIE BRONFENBRENNER, *THE ECOLOGY OF HUMAN DEVELOPMENT* (1979); SUSANNE CARTER, *THE IMPACT OF PARENT/FAMILY INVOLVEMENT ON STUDENT OUTCOMES: AN ANNOTATED BIBLIOGRAPHY OF RESEARCH FROM THE PAST DECADE 21-37* (2002), available at <http://www.directionservice.org/cadre/pdf/The%20impact%20of%20parent%20family%20involvement.pdf>; *Promoting Family Outcomes*, *supra* note 60, at 678-80.

171. Some scholars posit that the key mediating factor is dedication, since parents usually have a higher level of emotional investment in their child than any therapist or educator. Another line of thought is that the key mediating difference is time, since parents spend a huge number of waking hours with the child compared with the number of waking hours the child spends with therapists and educators. See Brooks-Gunn et al., *supra* note 69; *Recommended Outcomes*, *supra* note 61, at 229-30; Carl J. Dunst, *Parent-Mediated Everyday Child Learning Opportunities: I. Foundations and Operationalization* (2006), available at http://fipp.org/Collateral/caseinpoint/caseinpoint_vol2_no2.pdf. Both lines of thought inform the view commonly expressed in law that parents are the preferred decision-makers in the lives of their children. See, e.g., Parham v. J.R., 442 U.S. 584, 602 (1979); Troxel v. Granville, 530 U.S. 57, 69 (2000); Anne L. Alstott, *What Does a Fair Society Owe Children—And Their Parents?*, 72 *FORDHAM L. REV.* 1941, 1943-46 (2004).

172. See Brooks-Gunn et al., *supra* note 69, at 549; CARTER, *supra* note 170.

173. See Anne T. Henderson & Karen L. Mapp, *A New Wave of Evidence: The Impact of Schools, Family, and Community Connections on Student Achievement*, SW. EDUC. DEV. LAB., available at <http://eric.ed.gov/PDFS/ED474521.pdf> (providing a literature review about positive impact on educational achievement of children when parents and communities were involved in schools).

that schools looking for high achievement on the part of the children in special education as well as in general education seem to be well advised to get parents involved in the educational effort.¹⁷⁴

Parental involvement must turn, at least in part, on paying attention to what parents need. After engaging a wide variety of stakeholders in a consultative process, researchers for the U.S. Department of Education agreed that schools should try to achieve success on five measures of family outcomes when children are young:¹⁷⁵

- (1) Families understand their child's strengths, abilities and special needs.¹⁷⁶
- (2) Families know their rights and advocate effectively for their children.¹⁷⁷
- (3) Families help their children develop and learn.¹⁷⁸
- (4) Families have support systems.¹⁷⁹
- (5) Families access desired services, programs, and activities in their community.¹⁸⁰

What these measures share is a focus on parental competence and parental resources. Parents who have access to information about their child, their community, and their rights can use their existing competencies and develop new ones. Similarly, parents need the resources of support systems and advocacy skills if they are going to be able to help their children succeed.

Collecting data about these outcomes, the researchers concluded, would provide information about what kinds of programs serve families with young children in special education and what

174. See, e.g., Sammy J. Spann, Frank W. Kohler & Delann Soenksen, *Examining Parents' Involvement in and Perceptions of Special Education Services: An Interview with Families in a Parent Support Group*, 18 FOCUS ON AUTISM & OTHER DEVELOPMENTAL DISABILITIES 228 (2003); William Jeynes, *A Meta-Analysis of the Efficacy of Different Types of Parental Involvement Programs for Urban Students*, 47 URB. EDUC. 706 (2012). Other studies come to a different conclusion. See, e.g., Doreen J. Mattingly et al., *Evaluating Evaluations: The Case of Parent Involvement Programs*, 72 REV. EDUC. RES. 549 (2002); Dalun Zhang et al., *The Impact of Basic-Level Parent Engagements on Student Achievement: Patterns Associated with Race/Ethnicity and Socioeconomic Status (SES)*, 22 J. DISABILITY POL'Y STUD. 28 (2011); Eva M. Pomerantz, Elizabeth A. Moorman & Scott D. Litwack, *The How, Whom, and Why of Parents' Involvement in Children's Academic Lives: More Is Not Always Better*, 77 REV. EDUC. RES. 373 (2007).

175. *Recommended Outcomes*, *supra* note 61; see *Promoting Family Outcomes*, *supra* note 60, at 669–74.

176. *Id.* at 242, 244.

177. *Id.* at 242.

178. *Id.* at 244.

179. *Id.*

180. *Id.* at 244–45.

differences those programs make in the lives of the families as well as the children.¹⁸¹ Unfortunately, the waxing and waning of interest in parent-oriented policies and practices has put the necessary data collection out of reach, at least at the present time.¹⁸² The argument for pragmatism, therefore, while good, may be incomplete because of the lack of data. Even if it cannot stand alone, the pragmatism rationale adds support to proposals for changing special education law to take into account parental interests in support for competence and conservation of resources.

C. Social Justice for Parents of Children with Special Needs

Achieving social justice for parents of special needs children so that their lives differ less from those of parents of other children could be an important result of reforming special education to pay attention to parental needs. The lives of many parents with special needs children differ significantly from the lives of other parents. Among other things, their medical expenses are usually higher, while their household income is usually lower.¹⁸³ Their rates of family formation are lower, while their divorce rates are higher.¹⁸⁴ The hours spent providing supervision, therapy, and physical care for their children are often extremely high, while their opportunities for relationships with extended family and friends are often restricted.¹⁸⁵ Accessing special education for their children can contribute to these differences, particularly when the parents' needs for competence and resources are ignored.

181. Unfortunately, the recommended data collection has not been mandated by the Department of Education, so the conclusions of the researchers have not been fully investigated. See Donald B. Bailey, Melissa Raspa & Leslie C. Fox, *What Is the Future of Family Outcomes and Family-Centered Services?*, 31 TOPICS IN EARLY CHILDHOOD SPECIAL EDUC. 216 (2012).

182. See *id.* at 218–19.

183. See Czapanskiy, *Chalimony*, *supra* note 5, at 265–67 (explaining the employment rate of householders with child with disability was 73.5 percent, compared with eighty-three percent of other householders with children; poverty rate for families with child with disability close to twice that of other families); NAT'L ALLIANCE FOR CAREGIVING & AARP, *supra* note 25, at 7–8 (finding nearly a third of caregivers for children with special needs report a high degree of financial hardship; fifty-three percent are employed, compared with sixty-four percent of all adults, and their rates of part-time employment exceed those of other adults).

184. See Czapanskiy, *Chalimony*, *supra* note 5, at 269–70 (finding rates of divorce and single-parent households higher by at least five percent where family includes a child with special health care needs).

185. See NAT'L ALLIANCE FOR CAREGIVING & AARP, *supra* note 25, at 3, 7 (2009) (stating that, on average, caregivers of children with special needs report spending 29.7 hours a week helping the child with activities of daily living and performing other supportive services, including managing medical treatments, working with school, etc.; sixty percent of caregivers for children with special needs report that caregiving limits time for family and friends).

One way to examine social justice issues is through the capabilities approach (CA) to justice, which is advanced by Martha Nussbaum, a prominent political and legal philosopher whose focus includes questions about the scope of government responsibilities toward citizens.¹⁸⁶ Nussbaum argues that opportunities for humans to develop certain capacities are so fundamental to being human that justice requires the government to protect and support the achievement of a basic level of each capability by each person under its governance.¹⁸⁷ Education is one of the capabilities, and it is foundational for the achievement of others.¹⁸⁸ CA demands, as a matter of justice, that governments expend resources to ensure that every child has access to education.¹⁸⁹

The question then becomes whether CA places the same demand on parents: as a matter of justice, should parents also be required to expend resources to ensure that their child is educated? The instinctive answer may be an unconditional yes, and CA offers no objection to that conclusion where there is no conflict of interest between the parent and the child. CA demands additional consideration, however, in situations where the resources available to the parents are limited.¹⁹⁰ What if, for example, supporting the child's education means that the parents are deprived of sufficient resources for self-support? Recall that Susie's mother Barbara lost her job because she was called to school to assist with Susie on multiple occasions. Barbara's situation, not an unusual one for parents of special needs children,¹⁹¹ puts her at risk of not being able to support herself. CA requires that achievement of capabilities be measured at the individual level.¹⁹² Justice is not achieved, in other words, if most people have adequate resources but twenty percent do not. A parent cannot be required to sacrifice his or her own capabilities, therefore, to provide for a child's education. Put another way, if a parent must make such a sacrifice, the parent has the right, under CA, to call on the government for support for the child's education.

To some degree, the nature of the support depends, under CA, on the resources the country can provide in light of its wealth or

186. See Nussbaum, *supra* note 162.

187. *Id.* at 12–15.

188. *Id.* at 11–15.

189. *Id.* at 15, 69–72.

190. *Id.* at 23 (in contrast to libertarianism, for example).

191. See Czapanskiy, *Disabled Kids*, *supra* note 5, at 66; Yoanna X. Moisesides, *I Just Need Help . . . TANF, the Deficit Reduction Act, and the New "Work-Eligible Individual"*, 11 J. GENDER RACE & JUST. 17, 27–34 (2007).

192. Nussbaum, *supra* note 162, at 14.

poverty.¹⁹³ In a poor country, what Charlie and Susie receive through the public school system probably satisfies CA. The children are included in the educational system at no financial cost to their parents, and they will be provided with sufficient resources to achieve basic literacy and numeracy if those achievements are within their set of abilities. The greater resources of the United States, on the other hand, should mean that justice requires a higher level of investment in the education of special needs children. For example, the transition between early intervention services and preschool should be seamless. A young child should not lose time from school, as Susie did, because two government units fail to coordinate, assuming that the costs to the public of coordination are less than costs to the parents resulting from the failure to coordinate.

CA also supports the consideration of universal design approaches, such as RTI, as a reasonable expectation.¹⁹⁴ Because of RTI, Charlie moved through kindergarten along with the other children, so Martin and Eleanor could put their energy into his emotional and behavioral development as he made the transition from preschool. Once Charlie failed to benefit from the usual interventions, Eleanor and Martin had to take on the extra burden of working with the school to develop an IEP. By that time, however, Charlie's parents and the teacher had already shared experiences working with Charlie, information about what educational approaches worked, and relationships with experts at the center.¹⁹⁵ It is little wonder that Charlie's parents and school could agree on an IEP with little difficulty, while developing an IEP for Susie took many months and an unsuccessful resort to litigation.

Professor Anne Alstott, who specializes in taxation as well as social welfare and law and policy, has identified another rationale for

193. Rosalind Dixon & Martha C. Nussbaum, *Children's Rights and a Capabilities Approach: The Question of Special Priority*, 97 *CORNELL L. REV.* 549, 586–87 (2012) (explaining that a cost-effectiveness principle under a capabilities approach cannot limit the responsibilities of the government in a place like the United States, where “resource constraints do not actually prevent the state from protecting the capabilities of all citizens”).

194. RTI is expensive to develop, of course, but a possibility exists for federal funding for a portion of the costs. See Ciolfi & Ryan, *supra* note 149, at 305–06 (describing amendments to IDEA permitting federal funding for RTI); MARYLAND STATE DEPARTMENT OF EDUCATION, *A TIERED INSTRUCTIONAL APPROACH TO SUPPORT ACHIEVEMENT FOR ALL STUDENTS: MARYLAND'S RESPONSE TO INTERVENTION FRAMEWORK* (June 2008) (encouraging local school systems to implement RTI because of likely benefits to students but recognizing cost issues, despite availability of federal funding for some expenses).

195. See MARKOWITZ ET AL., *supra* note 48, at 53–57 (2006) (describing transition techniques employed by teachers).

considering fairness to parents when communities decide what resources to dedicate to children.¹⁹⁶ In contrast to the historical role of parents, which was characterized by reciprocal claims of children on parents to raise them and of parents on children for support as they age, modern parenthood is more of a one-way street from which parents are permitted “no exit.”¹⁹⁷ Parents, of course, derive joy and satisfaction from their role, but their level of personal, economic, and emotional sacrifice has risen dramatically at the same time that social and legal norms appropriately give parents fewer ways to exit from all or part of their responsibilities.¹⁹⁸ Alstott argues that a modern society should not require that parents fulfill their demanding role while leaving them unsupported.¹⁹⁹ Instead, the degree of sacrifice parents should be expected to bear should be examined critically in light of the social and legal expectations that parents provide continuity of care for their children from birth, at least through the first two decades of the child’s life.²⁰⁰ As Alstott puts it:

Many life projects are legitimately the subject of state regulation that renders them more expensive than otherwise The “No Exit” obligation represents an exceedingly rare exercise of a power that only the state should wield—the power to prevent citizens from revising their conception of the good. The state should exercise that power rarely; and when the exercise of that power is justified by some collective aim, society as a whole should take part in ameliorating the consequences for individual autonomy What I am suggesting is that it may be best to think of child-rearing as an endeavor with both public and private costs. Parents should be responsible for costs that reflect their “private” taste for resource consumption (in lifestyle and style of child-rearing), but the childless should bear some responsibility for ensuring that each child has access to the (publicly-defined) conditions of autonomy, especially when the state’s mandate proves extraordinarily costly for ordinary parents.²⁰¹

196. Alstott, *supra* note 171, at 1941–42.

197. *Id.*

198. *Id.*

199. *Id.*

200. *Id.* at 1942–46 (explaining “continuity of care” and its importance to children).

201. *Id.* at 1974.

One example of extraordinary cost is the care required for a special needs child, as Alstott notes.²⁰² As to these and other parents who are required to sacrifice for the good of the child, Alstott argues that society has a responsibility to mitigate or even share some of the costs.²⁰³ Her argument therefore supports the claim that fairness to parents should be taken into account when deciding how to provide special education because many parents experience unusual hardships while pursuing special education for their children.

Most obviously, parents seeking special education for their children may hire an attorney to represent them in their dealings with the school system, which is something parents seeking general education for their children need not do. Parents cannot shift that cost to the school system unless they prevail in a hearing or litigation, and even that avenue is limited.²⁰⁴ Further, attorney's fees incurred by the school system can be levied against parents, albeit under limited circumstances.²⁰⁵ Parents who disagree with a school system's assessment of their child may hire their own expert to prepare a report, a cost that may not be recoverable.²⁰⁶ Particularly well-resourced parents may place their child in a private school before a school system agrees that such a placement is appropriate.²⁰⁷ Reimbursement is available when parents prevail, but it may take years before that happens, and, in the meantime, parents are unable to use the money.²⁰⁸

Parents also risk losing financial resources because a child's need for special education may require so much time as to interfere with their employment.²⁰⁹ Many parents find that, in addition to meeting with teachers and school personnel, they need to spend

202. *Id.* at 1953–54.

203. *Id.* at 1954.

204. See 20 U.S.C. §§ 1415(i)(3)(B)(i)(I) (2006); see Pasachoff, *supra* note 1, at 1445–52 (explaining attorneys' fees provisions of IDEA and concluding that, "[e]ven if it were politically feasible, then, changing the rules about when attorneys' fees may be awarded is not likely to significantly ameliorate the IDEA enforcement disparities" favoring wealthier parents over poorer parents).

205. See 20 U.S.C. § 1415(i)(3)(B)(i)(II)–(III) (2006).

206. See *Arlington Cent. Sch. Dist. Bd. of Educ. v. Murphy*, 548 U.S. 291, 293–94 (2006) (holding that § 1415(i)(3)(B) does not authorize an award of expert witness costs as fees to prevailing plaintiff parents).

207. See Hyman, et al., *supra* note 58, at 121–26 (explaining how the reimbursement system under IDEA effectively limits remedy to well-resourced parents).

208. *Id.*

209. See NAT'L ALLIANCE FOR CAREGIVING & AARP, *supra* note 25, at 2–3, 8 (finding that seventy-two percent of caregivers of children help by, among other things, "advocating on [the child's] behalf with schools"; on average, caregivers spend almost thirty hours a week providing care and supportive services in ways not required of parents with children with ordinary needs; only thirty-five percent of caregivers of special needs children work fulltime, as compared with sixty-four percent of all adults).

considerable time researching the child's problem, identifying educational approaches and therapies, advocating for the child, coordinating neuropsychological and other testing, meeting with lawyers and experts, and, once a plan is in place, monitoring what happens in the classroom.²¹⁰ Further, as happened in Susie's case, a parent may need to be on call even after an IEP is in place.²¹¹

Alstott's argument does not require compensating parents dollar-for-dollar for costs and losses. It does, however, support reconsideration of the system in order to conserve the financial resources of parents while not reducing the educational benefits for the children. The critical reexamination that Alstott calls for would support reforms such as those suggested earlier, particularly to the extent that reforms may conserve parental resources.

D. Fairness Among Families with Special Needs Children

From the mid-1970s, when the exclusion of special needs children from public education first began to attract broad attention from courts, legislators, and scholars, concerns were expressed that some children would receive more resources than others and that resource allocations might turn on the wealth and other attributes of the child's parents, including race.²¹² Those concerns have merit. Children of parents with fewer economic resources and children in poorer school districts are demonstrably worse off than children whose parents have greater economic resources and those in wealthier school districts.²¹³ Children whose parents are highly educated and experienced in advocacy are likely to do better in special

210. Phillips, *supra* note 106, at 1827–37.

211. See Honig v. Doe, 484 U.S. 305, 312–16 (1988) (describing IEPs which included emotionally disturbed children being educated at home or in half-day programs).

212. See Pasachoff, *supra* note 1, at 1426 (noting that numerous scholars and commentators have provided “repeated examples of parents with greater financial resources disproportionately taking advantage of the IDEA’s private enforcement mechanisms”); Theresa Glennon, *Race, Education, and the Construction of a Disabled Class*, 1995 WIS. L. REV. 1237, 1321–22 (1995) (highlighting that predominantly African-American or minority school districts receive significantly fewer financial resources and may not be able to provide the services needed to prevent students with difficulties from falling further behind); Kirp, Buss & Kuriloff, *supra* note 2, at 55 (highlighting the efforts of the courts and legislators in trying to ensure that minority students are not disadvantaged with regards to special needs classes).

213. See Pasachoff, *supra* note 1, at 1426–29; Hyman, et al., *supra* note 58, at 109–10.

education than other children.²¹⁴ Where parents can afford counsel, they are likely to achieve better results for their children.²¹⁵ Since the special education system demands substantial time, energy, and sophistication on the part of parents seeking individual treatment for their children, households with only one parent are likely to have less capacity to get the school to pay full attention to a child.²¹⁶ Many of the children getting the poorest treatment in special education are children of color.²¹⁷

Paying attention to the inequalities experienced by the children is an essential step toward change. Focusing on what happens to the parents, especially in terms of supporting their competence and conserving their resources, should help to achieve that goal. One way to conserve, and even enhance, the resources available to every parent is to give groups of parents of special needs children incentives to work together, regardless of the resources they possess individually. This works well in general education, where all parents with children in a school system have a common incentive to seek resources for the schools. Others in the community may well share the goal of educating children, but their personal interests differ from those of parents.

Some parents already have an incentive to work together and pool resources to obtain educational benefits for all children with the same condition as their own child. For example, all parents with children in wheelchairs share an interest in architectural changes in schools to make them accessible. All parents with children with asthma share an interest in having a school nurse in the building

214. See Pasachoff, *supra* note 1, at 1436, 1443; Phillips, *supra* note 106, at 1836–37 (noting that a parent with fewer resources needs more assistance to effectively advocate for child).

215. See Hyman, et al., *supra* note 58, at 114; Pasachoff, *supra* note 1, at 1436 (noting that transaction costs of seeking special education are relatively high where parents have fewer economic, social, and educational resources and that wealthier parents are more successful in gaining IEPs they think desirable with assistance of lawyers and other experts); MELANIE ARCHER, ACCESS AND EQUITY IN THE DUE PROCESS SYSTEM: ATTORNEY REPRESENTATION AND HEARING OUTCOMES IN ILLINOIS, 1997–2002, at 7–9 (2002), available at <http://www.dueprocessillinois.org/Access.pdf> (concluding that attorney representation in due process hearings increases parents' chances of prevailing, making it equal to that of school districts); Sonja Kett & Jenai St. Hill, *Mediation of Special Education Disputes in Pennsylvania*, 15 U. PA. J. L. & SOC. CHANGE 179, 186–89 (2012) (finding that the presence of an attorney during mediation is positive for parents); Peter J. Kuriloff & Steven S. Goldberg, *Is Mediation a Fair Way to Resolve Special Education Disputes? First Empirical Findings*, 2 HARV. NEGOT. L. REV. 35, 55, 62–63 (1997).

216. See ONG-DEAN, *supra* note 4, at 6.

217. See Glennon, *supra* note 212, at 305–06 (noting overrepresentation of African-American boys in need of special education because of emotional disturbance); Hyman, et al., *supra* note 58, at 109–10.

who has been trained to respond to a child's breathing needs, especially in case of an emergency.²¹⁸

The difficulty arises when parents whose children have similar problems are in competition with each other for the same resources. Parents of children on the autism spectrum, like Charlie and Susie's parents, are an excellent example. Each child's parents can battle to obtain what they consider gold standard treatment for their child, regardless of what happens to any other child with the same issues. If a school system spends large sums of money on a few children, however, then the school system may find it lacks enough funds to provide every child with the same or even adequate services.²¹⁹ Given the individualized and privatized process now in place for establishing and monitoring IEPs, parents have every incentive to seek the maximum possible resources for their child.²²⁰ Even if Susie lived in the same jurisdiction as Charlie, she might not have access to the center, the smooth transition from early intervention to preschool, RTI in kindergarten, or parental support activities. Local agencies are required to protect the privacy of every family, so Susie's parents might not even know that Charlie is getting a better start in his educational experience.²²¹ Charlie's parents, on the other hand, have no incentive to help Susie's parents get a better plan for her. After all, if local agencies decide to spend more money meeting Susie's needs, they might decide to spend less meeting Charlie's.

The rulemaking or standard-setting approach proposed earlier helps give all parents an incentive to advocate for first-rate treatment for all children with similar conditions. If there were a rule or standard applicable to all similar children, no parent would be able to get gold-standard treatment for his or her child through the individualized system. The only way to achieve the gold standard for one child would be to successfully advocate for a gold standard for all children with similar conditions. Higher-resourced parents would have every incentive to participate in the process through which the rule or standard was established in order to advocate for

218. See Pasachoff, *supra* note 1, at 1440–43 (explaining that positive externalities are sometimes created when wealthier parents achieve superior special education plan for child, but unlikely where parents are in competition for school's resources).

219. See *id.* at 1436–37.

220. *Id.*; see also Caruso, *supra* note 99, at 182–84 (stating that school administrators may be inclined to provide equal services to children of low-resource parents once those services are being provided to high-resource parents, but high-resource parents have no incentive to advocate such result because education is a zero-sum game).

221. See Pasachoff, *supra* note 1, at 1437–41 (stating that information asymmetries protect privacy in special education but result in distributional inequities).

the best approach they think useful for their child. A positive externality would be that all children, regardless of the advocacy opportunities or skills of their parents, would have the benefit of whatever rule or standard was established. Further, parents with fewer resources could participate in the process but at a low-investment level. They could conserve what they had, whether that was time, energy, or money, in the expectation that higher-resourced parents would advocate strongly for an effective approach.²²²

CONCLUSION

Since the 1970s, legal reforms requiring schools to be open to children with learning disabilities and special needs have made an enormous difference in the lives of the children and their parents. Parents are no longer left to do the best they can for their special needs children without help from the local school system. Parents can demand that local schools include their child and attend to their child's needs. The procedures can be daunting, but the benefits can be great and enduring.

During the same four decades, social, economic, and medical practices have combined to place increasing demands on many parents of special needs children. Many more households depend on the earnings of both parents, where there are two,²²³ and fewer households include two adults.²²⁴ Less public support is available to parents who are not in the labor force.²²⁵ More children with disabilities and chronic illnesses live to adulthood outside of institutions.²²⁶ Chronic medical conditions are more commonly managed with frequent daily interventions, usually administered by a parent.²²⁷

222. Differential treatment of children may decrease as well in schools adopting universal design pedagogic approaches, which also, as discussed earlier, reduce the strains on parental resources while supporting parental competence.

223. See generally PEW RESEARCH CTR., BREADWINNER MOMS 20 (2013), available at http://www.pewsocialtrends.org/files/2013/05/Breadwinner_moms_final.pdf.

224. Czapanskiy, *Chalimony*, *supra* note 5, at 269–70.

225. See Moisesides, *supra* note 191, at 22–25 (explaining work participation requirements for people seeking welfare); Noah Zatz, *Welfare to What?*, 57 HASTINGS L.J. 1131, 1138–40, 1177–79 (2006) (using TANF and EITC to demonstrate a change in transfer programs for low-income families to require earnings or participation in the labor force).

226. Czapanskiy, *Disabled Kids*, *supra* note 5, at 50–52 (describing declines in institutionalization practices affecting younger children).

227. Czapanskiy, *Chalimony*, *supra* note 5, at 260–63 (describing daily healthcare regimens and environmental monitoring performed by parents of children with asthma); Czapanskiy, *Disabled Kids*, *supra* note 5, at 56 (highlighting the frequency and type of care that parents provide to children with special needs).

Given all the demands on their time, energy, and money, parents of special needs children are stressed. Public policy can reduce the stress by paying attention to supporting parental competence and helping parents conserve their resources. Three changes have been proposed here: helping parents communicate with each other, committing to common educational plans for children in similar situations, and preferring universal pedagogic practices. Each would enhance support for parental competence while, at the same time, helping parents conserve their resources of time, energy, and money. Each is a justifiable use of public funds because each is likely to advance the congressional mandate, to benefit the affected children, to diminish the differences between families raising a special needs child and other families, and to reduce the disparities in resources devoted to special needs children in higher-resourced families as compared with lower-resourced families. The changes proposed here are not, however, the only ones that can accomplish these goals, and others can be proposed and measured against the same criteria.

While special education is a good example of an area of public policy that needs to be reconsidered in light of the special needs of parents of special needs children, it is not unique. Changes need to be made in the law governing private family relationships²²⁸ and in federal law governing public benefits, among others.²²⁹ As that work broadens and deepens, we can look for impressive improvements in the lives of special needs children as well as their parents. In the interim, the proposals here will contribute to the capacity of special parents to meet the needs of their special children.

228. Czapanskiy, *Chalimony*, *supra* note 5, at 254–55 (arguing that family laws should require nonresident parents to provide additional financial assistance to the caretaker parents of children with disabilities).

229. Czapanskiy, *Disabled Kids*, *supra* note 5, at 46 (“Public benefits should be available to disabled children and their co-resident caregivers in amounts adequate to ensure that the household standard of living is high enough to reward and appreciate home-based caregiving.”).