## Chapter 3

# Legislation, Program Development, and Service Delivery

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Although autism was recognized and identified in the early 1960s, education and treatment programs at that time were scarce. Nevertheless, parents were organizing and initiating programs for their children with autism. The history of autism legislation reflects the same confusion that education and health professions encountered when trying to provide services to children with autism and their families. Unarguably, the most important legislation for children and youth with disabilities was IDEA (Individuals with Disabilities Education Act). However, bowing to political demands, autism was not listed as a category under IDEA until 1990. Still, individuals with autism were eligible for some services under other disability legislation. A dramatic increase in numbers of persons identified with autism burst into the public consciousness through personal accounts from movies, books, and advocacy groups and changes in legislation, program development, and service delivery expanded at the same time. This chapter provides information on legislation that helped define the programs and service delivery systems designed to meet the growing need.

## Legislation Impacting Individuals with Autism

Over the decades, as information concerning autism has expanded, the "growing prevalence of ASD is shaping current law and policy relating to all disabilities and will have a profound impact on children with disabilities, particularly concerning special education" (Dicker & Bennett, 2011, p. 416). Table 3.1 lists key legislation related to Autism Spectrum Disorders (ASD).

Autism originally was known as a low incidence category, inferring that the numbers of children with this type of disability were few. As a result, prior to 1975, children with autism were routinely excluded from attending schools because of the belief that they could not learn or that they would interfere with the learning of other students in the class (Dicker & Bennett, 2011; Hass, 2008). Thus, many children who would

*Table 3.1* ASD Legislation

| *ASD Legislation* |
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| Achieving a Better Life Experience Act (ABLE) of 2014, Public Law 113–297, 26 U.S.C. § 529 |
| Autism CARES Act of 2014, Public Law 113–157, 42 U.S.C. 201 *et seq.* |
| Children's Health Act of 2000, Public Law 106–301, 42 U.S.C. 201 *et seq.* |
| Combatting Autism Act of 2006, Public Law 109–416, 42 U.S.C. 201 *et seq.* |
| Combatting Autism Reauthorization Act of 2011, Public Law 112-32, 42 U.S.C. 201 *et seq.* |
| Developmental Disabilities Assistance and Bill of Rights Act 2000. Public Law 106–402, 42 U.S.C. § 6000 *et seq.* |
| Education for All Handicapped Children Act of 1975, Public Law 94–142, 20 U.S.C. § 1471 *et seq.* |
| Education of the Handicapped Act of 1970, Public Law 91-230, §§ 601–662, 84 Stat. 175. of 1986, 20 U.S.C. § 1401 *et seq.* |
| Education of the Handicapped Act of 1974, Public Law 93-380, 20 U.S.C. § 1232 *et seq.* |
| Elementary and Secondary Education Act (ESEA) of 1965, Public Law 89–10, 20 U.S.C. § 16301 *et seq.* |
| Elementary and Secondary Education Act, amended by Public Law 89–750. 20 U.S.C. § 161 [Title VI], 80 stat. 1204 (1966). |
| Handicapped Children's Protection Act of 1986, Public Law 99–372, 20 U.S.C § 1401 *et seq.* |
| Higher Education Opportunity Act of 2008, Public Law 110–315, 20 U.S.C.§ 1001 *et seq.* |
| Individuals with Disabilities Education Act of 1990, Public Law 101–476, 20 U.S.C. § 1400 *et seq.* |
| Individuals with Disabilities Education Act Amendments of 1997, Public Law 105–17, 20 U.S.C. § 1400 *et seq.* |
| Individuals with Disabilities Education Improvement Act of 2004, Public Law 108–446, 20 U.S.C. § 1400 *et seq.* |
| No Child Left Behind Act of 2001. Public Law 107–110, 20 U.S.C. 70 § 6301 *et. seq.* |
| Patient Protection and Affordable Care Act of 2010, Public Law 111–148, 42 U.S.C. § 18001 *et seq.* |
| Rehabilitation Act of 1973, Section 504, Public Law 93–112, 29 U.S.C. § 794 *et seq.* |

now be considered as having autism were labeled under the category of mental retardation or emotional disturbance, spending the majority of their lives in an institutional setting. As a result, much of the pre-1990 legislation did not include autism specifically as a category of disability. A brief description of legislation that was important in the provision of services for children with autism and other disabilities follows.

### Rehabilitation Act (Section 504) (Public Law 93–112)

Public Law 93-112, known as the Rehabilitation Act, was enacted in 1973. It was an expansion of several earlier acts beginning in the early

1900s with the Soldier's Rehabilitation Act (1918). One part of the Act, Section 504, is considered to be the part of this legislation that focuses on nondiscrimination of individuals with a disability. Specific categories of disability are not included in the Rehabilitation Act as it used a functional definition focusing entirely on the existence of a disability and its impact on the individual's chances for success. The Rehabilitation Act is basically civil rights legislation for persons with disabilities and, as such, is more inclusive in its outlook than other education-focused pieces of legislation, such as the Individuals with Disabilities Education Act.

### *Developmental Disabilities Assistance and Bill of Rights Act (Public Law 106–402)*

There has been ongoing controversy over the classification of persons with mental retardation and other disabilities and how should they be identified. As a result of this moral question, in 1975 a new more global category was invented—developmental disabilities (Eyal, Hart, Onculer, Oren, & Rossi, 2010). This piece of legislation was an amendment of a 1963 act known as the Mental Health Centers Construction Act. The act included a variety of changes including a functional, as opposed to a categorical, definition of disability, i.e. developmental disabilities (DD), and an expansion of state involvement through state plans, state grants and State Developmental Disabilities Councils.

In addition, it included a Bill of Rights for Persons with Disabilities. Because it includes a functional definition, autism was not named specially, although individuals could be served under the eligibility rubric of DD. This piece of legislation was most recently reauthorized in 2000 to continue its focus on programs for individuals with developmental disabilities (Title I), family support (Title II), and programs for direct support workers who assist individuals with developmental disabilities (Title III).

### *Education for All Handicapped Children Act (Public Law 94–142)*

In 1975, a piece of legislation considered to be the most important in this century for persons with disabilities was enacted. The Education for All Handicapped Children Act (EAHCA) essentially included a Bill of Rights for Children with Disabilities with the assurance that all children with disabilities receive a free, appropriate, public education, abbreviated as FAPE (Murdick, Gartin, & Fowler, 2014). Thirteen specific categories of disability were listed and explicitly covered by this legislation. Autism was not included as one of these, as it still was considered to be a rare disability. As such, autism was subsumed within the disability category of *seriously emotionally disturbed (SED)* and later in 1981 moved to the *other health impaired (OHI)* category (Zager, Wehmeyer, & Simpson, 2012). The EAHCA was amended once more before the new decade began. The Education of the Handicapped Amendments (EHA) of 1986 included two new programs addressing the needs of infants and toddlers with disabilities and also pre-school children ages three to five years old. Although the law was expanded, still autism was not included as a separate category in the legislation.

As the country moved into the 1990s, autism finally was recognized as a separate category. It was believed that by specifically naming autism as a category, more appropriate research, education, and legislation could be provided for individuals with autism and their families. Subsequently, during the past 25 years, the number of pieces of legislation that have included or focused on children with autism has increased, as has research on ASD.

### *Individuals with Disabilities Education Act and its Reauthorizations (Public Laws 101–476, 105–17, and 108–446)*

In 1990, a more extensive reauthorization of the EAHCA occurred, including a name change to reflect the field's move to focus on people first language. Thus, the new law was entitled the Individuals with Disabilities Education Act (IDEA) of 1990. Additional changes included expansion of service delivery to students with disabilities ages 18–21 years old, inclusion of transition services and assistive technology as approved special education services, and rehabilitation counseling and social work services under the list of related services. But to the field of autism, the most important aspect was the inclusion of autism as a specific, freestanding category for the first time (Murdick et al., 2014). The law has been reauthorized and revised three more times since. The first reauthorization was in 1991, titled the Individuals with Disabilities Education Act Amendments (IDEAA) with changes in the Part H program for infants and toddlers and the inclusion of an Individualized Family Service Plan (IFSP) instead of an Individualized Education Plan (IEP) for children ages three to five. Again, the law was reauthorized in 1997, with changes focusing on school safety, parental participation, and finance.

In 2004, a major revision of IDEA was completed. This reauthorization, known as the Individuals with Disabilities Education Improvement Act (IDEIA), included a definition of highly qualified special education teachers, a provision for reducing paperwork, appropriate education for homeless or migrant children, changes in procedural safeguards, and a revision of state performance goals and requirements to bring IDEIA into compliance with the reauthorization of Elementary and Secondary Education Act (ESEA) of 1965, now known as No Child Left Behind Act

(NCLB). In addition, this reauthorization addressed the programmatic needs of children with autism by calling for the development and expansion of programs to train teachers for this group of students (Dicker & Bennett, 2011) and to increase the use of research-based teaching methodologies (Zager et al., 2012). According to Murdick et al. (2014, p. 30), "the changes to IDEA may be seen as an attempt to reduce the conflict between IDEA and the No Child Left Behind Act (NCLB) of 2001 (P.L. 107–110)," that is, the individual focus of IDEA and the group focus of NCLB have led to concerns over the appropriateness of programming and assessment of student progress.

### *Children's Health Act (Public Law 106–310)*

The Children's Health Act of 2000 was signed by President Clinton to increase research and treatment in a variety of health issues including autism. There are five sections of the law that focus on the issues related to autism. Section 101 focuses on the "expansion, intensification, and coordination of activities of National Institutes of Health with respect to research on autism" (U.S. GPO, 2000). Section 102 focuses on developmental disabilities surveillance and research programs for individuals with autism, including the National Autism and Pervasive Developmental Disabilities Surveillance Program, the Centers of Excellence in Autism and Pervasive Developmental Disabilities Epidemiology, and a Clearinghouse at the CDC for storage of data generated under this section. Section 103 expands and implements a program to provide information and education in the field of autism to professionals and the general public. Section 104 of this law mandates the establishment of a group to oversee and coordinate research in the field of autism known as the Interagency Autism Coordinating Committee (IACC). The IACC's mission is to "facilitate the effective and efficient exchange of information on autism activities among the member agencies and to coordinate autism-related activities" (U.S. Department of Health and Human Services, 2003). And the final section, 105, requires a yearly report to Congress on the progress of these sections of the legislation.

### *No Child Left Behind Act (Public Law 107–110)*

The No Child Left Behind Act of 2001, or NCLB, is a reauthorization of the ESEA and is considered to be one of the most sweeping pieces of legislation since IDEA was first enacted in 1975. According to the Office of the Under Secretary of the U.S. Department of Education "[t]his historic reform gives states and school districts unprecedented flexibility in how they spend their education dollars, in return for setting standards for student achievement and holding students and educators accountable for results" (2002, p. 3). Thus, the purpose of the act is to "close the achievement gap by holding states, local school districts, and schools accountable for improving the academic achievement of children" (Wright, Wright, & Heath, 2004, p. 21). This focus on academic accountability through the use of state-developed tests becomes one of the most controversial, as there are concerns that the focus on testing as the means to identify progress may impact negatively on students with disabilities and those from minority or poverty-stricken areas of the country.

### *Combatting Autism Act and Reauthorizations (Public Laws 109–416, 112–32, and 113–157)*

The Combatting Autism Act (CAA) was enacted in 2006 by President Bush "in recognition of the rapid growth in the number of children diagnosed with autism" (White, Smith, Smith, & Stodden, 2012, p. 8). This Act provides federal funding for research, screening, intervention, and education for individuals with autism. The CAA was reauthorized by President Obama in 2011 as the Combatting Autism Reauthorization Act (CARA) in order to ensure the continuation of the research, early identification, and professional training that had begun under CAA. Again, CARA was reauthorized by Congress and signed by President Obama in 2014. It became law and was retitled as the Autism Collaboration, Accountability, Research, Education and Support Act, or Autism CARES Act. This Act reauthorizes the Combating Autism Act and continues funding for research in the identification of risk factors, treatments and interventions, services, and data collection for both children and adults on the autism spectrum for five years (the White House Blog, 2014).

### *Higher Education Opportunity Act (Public Law 110–315)*

The Higher Education Opportunity Act of 2008 is usually considered to focus on students with intellectually disabilities. The Act was the latest of many reauthorizations of the Higher Education Act of 1965, enacted to improve access to college or career schools for students with intellectual disabilities (ID) (Center for Autism Research, 2014; Lee, 2009). This Act provided increased access for these students to Pell grants and other financial aid opportunities for those students with intellectual disabilities who "are enrolled or accepted for enrollment in a comprehensive transition and postsecondary program at specific institutions of higher education (IHE) and maintain satisfactory progress in the program" (Lee, 2009). Although this act focuses on students with intellectual disabilities (ID), there is increasing evidence that many students with ID also have autism. According to the Center for Disease Control's (CDC) latest prevalence study of records since 2008, 10 percent of those individuals whose primary diagnosis is ID also have a secondary diagnosis of Autism Spectrum Disorder (ASD), and 38 percent of those individuals whose primary diagnosis is ASD have a secondary diagnosis of ASD (Center for Autism Research, 2014). As a result, professionals and parents addressing the programmatic needs and future plans for students with ASD should be cognizant of the provisions of this Act.

### *Affordable Care Act (Public Law 111–148)*

The Patient Protection and Affordable Care Act of 2010, commonly called the Affordable Care Act and signed by President Obama, includes a significant section for children with autism as individuals with ASD can face complex health needs throughout their lifespan (Autism Speaks, 2015a). For most families of children with autism, it is critical that they have some type of financial support to manage the variety of medical, behavioral, and developmental health services required for their child. According to Autism Speaks (2015a), this can require a complex navigation of multiple medical professionals and insurance reimbursement rules that may not cover all the needed services. As a result of this problem, many reported that they had to pay much of the medical costs themselves. With the enactment of the Affordable Care Act, insurance companies are prohibited from denying coverage to children with pre-existing conditions that include autism. The act also includes behavioral health treatments on its list of essential benefits. Even with this change, there continues to be concern that parents with fewer resources still will be unable to access appropriate services for their child with autism.

### *Achieving a Better Life Experience Act (Public Law 113–295)*

As noted previously, many individuals with disabilities (and their families) have had difficulty paying for their disability related services (Autism Speaks, 2015b). To address part of this issue the Achieving a Better Life Experience Act, or the ABLE Act of 2014, an amendment to the Internal Revenue Code of 1986, was signed by President Obama. Its purpose is to:

> (1) encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life; and (2) provide secure funding for disability-related expenses of beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, Title XVI (Supplemental Security Income)

> and Title XIX (Medicaid) of the Social Security Act, the beneficiary's employment, and other sources to allow parents to set up a special tax-free savings account for disability-related expenses.
>
> (Library of Congress, 2015)

Although major changes and legislative support expanded the options for individuals with ASD, problems still continue to arise. Most noteworthy is that children with autism who are high functioning may not be eligible to receive needed special education and related services because of the manner in which the regulations are written. In addition, the NCLB's focus on alternative testing for those with a disability may hamper the educational future of these students because these tests may be unable to adequately measure ability. Also, legislation is occurring across the states, which holds promise for children with autism and their families but also leaves concern that consistency of educational programming will not occur since all states could pass legislation with differing requirements.

## Program Development for Individuals with Autism

Developing an appropriate educational program for children and adolescents with autism is an essential, although sometimes difficult, task. Both IDEA and educational research agree that all programs should be based on an assessment of the individual's unique needs as well as his/her strengths. The focus of this assessment and subsequent program development has changed over time, moving from a deficit approach to a more child-focused, classroom approach.

### *Deficit Approach to Program Development*

According to Harry and Klingner (2007), special education service delivery, that is program development for educational programs, was based originally on the deficit model. This model views children with unique needs through the lens of difference and developmental limitations. Thus, teachers and other educators often see disability as something inherent in the child that needs to be remediated or eliminated. Unfortunately, those performing the individualized assessments did not consider other reasons for why the child might be unsuccessful in school or on assessment items. Disability in the view of the deficit model is difference, and differences need to be eradicated. According to Pfeiffer (2002, p. 3):

> there are three variations of the deficit model: the medical model, the rehabilitation model related to employment, and the special education

> model. Each model specifies a deficit (health condition, employment condition, learning condition) which must be corrected in order to make the person with a disability "normal."

The research and philosophy of special education originally was focused on this deficit model, with most children viewed from the perspective of the medical model which focuses on the health issues of the child. Thus, the diagnostic emphasis for a child with autism would focus on qualitative impairments in social reciprocity, atypical communication, and atypical behavior (Hyman & Towbin, 2007).

During the 1970s, a number of individuals began to question the use of the deficit model as the focus for decisions concerning eligibility for special education services (see Deno, 1970 and Blatt, Biklen, & Bogdan, 1977 for an early discussion of this issue). This discussion continues over the next 40 years with many espousing an entirely different viewpoint that moves completely away from this model to embrace the disability studies philosophy (Ware, 2011), while others continue using the deficit model because they are unwilling to totally discard the research and methodology developed under the earlier special education rubric. As Banks (2014, pp. 510–511) states in support of the change:

> Special education provides service and access to students and families who have varied life experiences that manifest as variations in development, learning, and behavior. If the initial statement is true and we, as a field, understand that the children and youth we serve are different, why is special education couched in a deficit service provision model?

### *Program Development for Children and Youth with Autism*

Program development for children and youth with autism and other disabilities has been the major focus since the early days of special education. As said previously, the issue often has arisen as to what type of programming is needed and where the program should be implemented. Today, most educators agree that, "at first glance, there may appear to be multiple goals of education. However, there is one absolute target for all students, including those with ASD: Preparation for Adulthood" (VA DOE, 2011, p. 8). What was and continues to be needed is a framework on which to base the development of an appropriate program. The appropriate education framework was initiated with the enactment of IDEA in 1975. Although initially IDEA was based on the medical model, reauthorizations provided significant movement toward a more inclusive, non-deficit view of identification and program development. As Banks (2014, p. 517) noted:

focusing on human variation as opposed to pathology has been argued as a viable option for moving special education from a deficit model to a model that embraces divergence, keeping in mind that difference is not unique but is the one variable that resonates in all people, including children and youth.

### *Early Intervention Program Development*

Recent research has long shown that by providing children with appropriate services and supports early in their life, significant gains in language, behavior, social skills, and eventually education can be made (ASGRC, 2011). With the IDEA reauthorization in 1986, service requirements were expanded to include children from ages three through five years old who were eligible under the law. This free, appropriate public education (FAPE) program was to be provided in the least restrictive environment (LRE) and to include both academic and behavioral goals that addressed the student's unique strengths and needs. In addition, a new section of the law was added to address the provision of early intervention services for young children with special needs, those from birth to age three years old who are experiencing a developmental delay: "The centerpiece of the infants and toddlers section of the law was the individualized family service plan (IFSP)" (Yell, 2014, p. 43). The IFSP should be developed by a multidisciplinary, interagency team that includes the parents as essential members. The IFSP is different from an IEP, as it focuses on the child as a member of a family system and looks at the unique needs of the child in his/her natural environment, his/her home. Between the ages of three and five years old, the child can be served by the school district by continuing use of the IFSP or transferring the child's educational planning to an IEP.

When the child transitions into the education-focused planning, then the program will be based on an assessment of the child's not the family's unique needs. This assessment must be a multidisciplinary assessment which has a twofold focus: to determine the child's eligibility for special education services under IDEA and to develop the educational program that will meet the child's needs. This multidisciplinary assessment is to be completed by the members of the multidisciplinary team. According to IDEA, the team should include the parents of the child with a disability, at least one regular education teacher of the child, at least one special education teacher, a representative of the local educational agency who is knowledgeable about curriculum and available resources and can provide or supervise such, an individual who can interpret the evaluation results, related service personnel as needed, and the child when appropriate (IDEA, 20 U.S.C. § 1414[d][B]).

Both the assessment and the program development should focus on the child's specific unique needs. Once these needs have been identified and the child has been declared eligible for services then the setting where this education program should be provided is identified. This service delivery should be considered on the basis of where the child's educational and social needs can best be met, not according to the eligibility label. The other requirement for the setting of the service delivery is that it be in the LRE for the particular child. As has been noted earlier, there is no specific "least restrictive environment," instead it is based on where the child can receive the most appropriate services as close to his/her peers in the general education classroom as possible.

### *Classroom-based approach*

For most children with autism, the general education classroom is the least restrictive environment where students have more opportunities to "learn from typically developing peers in naturalistic settings" (ASGRC, 2011, p. 102). Any programs in the general education, inclusive classroom will need adaptations for successful learning to occur. There are a number of research-based programs that focus on the education of students with autism. Three of these programs (TEACCH, ABA, and BI/FAB) will be briefly described.

#### *Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH)*

The TEACCH program is one of the earlier programs that were developed to address the specific needs of children with autism. Eric Schopler developed the TEACCH program in the 1960s. TEACCH focuses on the needs of children with autism "for an intensive and coordinated approach to skill building and developing communication abilities" (Hyman & Towbin, 2007, p. 335). TEACCH uses parents as co-therapists who teach new skills to their child with autism. The importance of teaching as a structured activity is also stressed, meaning that the adult plans the activity, secures the materials for use, determines the length of time for the session, and communicates the information clearly to the student (Mesibov, Shea, & McCaskill, 2012). As a result of this general view of program planning, TEACCH is considered to use an eclectic program format, which incorporates a number of different behavioral methods including applied behavior analysis (ABA).

#### *Applied Behavior Analysis (ABA)*

ABA "is science devoted to the understanding and improvement of human behavior" (Cooper, Heron, & Heward, 2007, p. 3). ABA is based on the pioneering work on the science of behavior by Watson and his

Stimulus-Response Behaviorism of the early 1900s and Skinner's Radical Behaviorism of the mid to late 1900s. From this foundation come studies that employed behaviorist principles to humans. Baer, Wolf, and Risley's 1968 seminal paper describes applied behavior analysis and explains that it "should be *applied, behavioral, analytic, technological, conceptually systematic, effective,* and capable of appropriately *generalized outcomes*" (Cooper et al., 2007, p. 16, emphasis added). Those who use this method believe that many student behaviors are learned; thus, students can learn new behaviors (Vaughan & Bos, 2012). Programs based on Applied Behavior Analysis incorporate intensive, early intervention and employ discrete trial training, prompting, and reinforcement of appropriate behaviors. Discrete trial training, or DTT, is a specific ABA method that has been shown to be effective in teaching children with autism. This method is used effectively in Lovaas' 1987 seminal work on using behavioral treatment with children with autism (Scott & Bennett, 2012) and in many classrooms today.

### *Behavior Intervention and Functional Analysis of Behavior (FBA)*

Behavior interventions are based on the belief that "behavior carries meaning and should not be presumed to be a random act" (Hyman & Towbin, 2007, p. 337). This presumption leads the way to a more effective assessment of the child's behavior and how it is related to the scenario in which it is occurring. From there, the multidisciplinary team can develop a behavior plan to address behaviors that may be hindering the success of the individual in his/her home, school, or community environment.

The process using functional analysis of behavior is also known as functional behavioral assessment or FBA. FBA is included in IDEA 1997 as a required step in the assessment and program development process. An FBA is "the process of gathering information about a learner's behaviors in order to determine the purpose of a problem behavior in addition to its antecedents and consequences" (Raymond, 2012, p. 42). This process allows the team to identify the behaviors of concern as well as the setting and context of the behavior and, more importantly, the possible function that the behavior serves for the individual (Cooper et al., 2007). Essentially the FBA is an attempt to identify the cause-and-effect relationship between the individual's behaviors, the environment in which the behavior occurs including the setting and the individuals present in the setting, and the presence of precursors of the behavior (i.e. antecedents, individual's responses, and reinforcement of the behavior). As Hyman and Towbin (2007, p. 337) explain, "If the origin of the behavior is considered, it may be possible to teach more effective ways to achieve a similar result (e.g., comfort, communication) and to expand behaviors that increase social adaptability."

### *Universal Design for Learning (UDL) Approach*

There is a continuing debate as to whether the most appropriate educational setting for students with autism is the general education classroom or not. For many parents and educators, education in the least restrictive environment, wherever that may be on the continuum of alternative placements, is the most appropriate site. For others, the most appropriate placement is the inclusive classroom. Inclusion is considered to be both a philosophy of education and an educational placement type. Those who consider inclusion as a philosophy believe that all children should have access to a quality education in the same setting as their neighborhood age peers. For an inclusive environment to be a successful placement for students with autism, teachers must develop accommodations and/or modifications in both curriculum and physical environments for use in addressing the child's unique needs (Clair, Church, & Batshaw, 2007). For teachers to do this successfully, many turn to the concept known as Universal Design for Learning (UDL), also known as Universal Design for Instruction (UDI). This concept is adapted from the concept of Universal Design in architecture and engineering, which focuses on developing designs that increase accessibility for persons with disabilities, but are useful for all (Hackman, 2008). According to the CAST website (2015), "Universal Design for Learning (UDL) is a research-based set of principles to guide the design of learning environments that are accessible and effective for all." In operation, UDL typically includes curriculum, curricular materials, instructional activities and procedures, and evaluation procedures and materials designed to meet the needs of *all* students in the classroom. Thus, the teacher reviews his/her classroom environment, curriculum and instruction, and materials and methods in order to identify which ones could be designed to meet the multiple needs and skills of all students in the classroom. Lessons and the classroom environment are revised so that they promote "access, participation, and progress in the general education curriculum for all learners by proactively embedding accommodations into instruction to meet learning needs of all students" (Heflin & Isbell, 2012, p. 192). The proactive behavior is in opposition to the retroactive identification and implementation of accommodations after the curriculum, lessons, activities, and settings are planned. Therefore, an educational program for a child with autism, or another disability, might include both placements in an inclusive classroom where UDL approaches are used and in classrooms where educational approaches and accommodations are designed specific to the child's unique needs.

## Parent Involvement

When one reviews the issues inherent in the provision of educational services for children with autism, the involvement of parents and families in the child's educational program is a principle present in all approaches (Hecimovic, Powell, & Christensen, 1999). The inclusion of parents is a significant change from earlier times, when parents often were blamed for their child's disability and seldom notified or included in any of the program developments or their implementation. Today, parent and family involvement is a requirement when the child with autism is receiving infant and toddler services. Parents are an essential part of the development of the IFSP and also in the implementation of the program delivery. As the child transitions into school-based services, family involvement continues. This involvement may be support in the home for the school-based program, or it may be involvement with interventionists who are providing behavioral treatment in the home. Parent involvement is best described by ten principles suggested by Hecimovic, Powell, and Christensen in 1999. These are: (1) children grow best in families; (2) family members are interdependent; (3) parents are the best judges of their children's needs; (4) the family is the best advocate; (5) families want involvement; (6) professionals need to support families; (7) parents should question professionals; (8) autism need not be negative; (9) concern is for the long term; and (10) there is more than autism (p. 265–266).

The family-centered approach described by the previous list and encapsulated in the IDEA legislation sees professionals and families as supporters of each other in the education of the child with autism. According to Dunst, Johanson, Trivette, and Hamby (1991), family- centered support promotes the family in learning to make decisions, in focusing on the capabilities and competencies of the family members, and in choosing resources and support to assist them in building a network to strengthen their capacity to work with their child. This collaborative approach requires that the professional be the ally of the family as the child moves through the educational system to reach his/her goal of life in the community (VA DOE, 2011). As a supportive family-centered ally, professionals assist families in addressing problems that may arise, such as lack of support within the community, individual and family member stress including that of siblings and extended family members, financial issues, marital stress, concerns over conflicting professional advice, and questions about professionals' knowledge base (Agosta & Melda, 1995; Hecimovic et al., 1999).

## Evidence-based Practices: The National Standards Project

In this chapter, the legislative background for program development and service delivery have been examined. Along with this discussion, program development and changes in educational philosophy have been examined as they relate to the placement of students and the involvement of parents. One area that has not been considered is the evidence base for practices and methods being used by professionals who work with students with autism. Some states have developed their own guides to assist the members of the multidisciplinary team on appropriate selection of evidenced-based practices for use with children with autism. For state examples, review Virginia's *Models of Best Practice* (2011), Ohio's *Autism Reaching for a Brighter Future* (2011), and Missouri's *Autism Spectrum Disorders: A Guide to Evidence-Based Interventions* (2012). On the national arena, one can access the National Standards Project Report (2009, 2015) for information about effective practices. According to the National Autism Center (2015), *The National Standards Report* answers the question of how to effectively treat individuals with autism spectrum disorder (ASD). This project was begun in 2005 by the National Autism Center in collaboration with an expert panel of scholars, researchers, and other national leaders. It is considered to be the most comprehensive analysis of evidence-based interventions for children and adolescents with autism (National Autism Center, 2015). The project was completed in two phases: Phase 1 from 2005 through 2009 and Phase 2 from 2009 through 2015. Phase 1 includes an examination and quantification of the level of research that support interventions targeted toward children, adolescents, and young adults with autism. Phase 2 provides an updated examination for this age group and extends the research base to adults over age 22.

According to the National Autism Center (2015), the National Research Project is an expansion of a 2001 report by the National Research Council (NRC). That report identifies effective practices such as early intervention, instructional programming, parent involvement, utilization of deliberate teaching, small group or one-to-one instruction, and a communication-rich environment (NRC, 2001). Even with the publication of that report, families, educators, and service providers were still confused with the myriad and sometimes conflicting information about available treatments. Thus, the 2015 report is seen as a much-needed step in "helping to reduce the resulting turmoil and uncertainty by addressing the need for evidence-based practice standards and providing guidelines for how to make choices about interventions" (National Autism Center, 2015, p. 1).

Services for persons with autism have developed quickly, but through research data educators and medical professionals learned some important principles. First, early intervention leads to better outcomes. Parent involvement is not only important, but it leads to better outcomes for both the child and the family. Autism spans all ages, but its impact differs according to the age of the person with autism. Thus, services must develop a lifespan approach. Finally, the National Standards Project report identified effective practices such as early intervention, instructional programming, parent involvement, utilization of deliberate teaching, small group or one-to-one instruction, and a communication-rich environment as a result of a thorough examination of research data. The next section provides information on the strategies used for the delivery of services to the children with autism and their families.

## Service Delivery

In earlier times, the diagnosis of autism was the pivotal point for a decision as to where the student would receive his/her services. The diagnosis driven decision-making changed during the past 40 years, so that now "educational placement decisions must be based on the assessed strengths, challenges, and educational needs of the student rather than on the label of autism" (VA DOE, 2011, p. 26). In other words, the disability label of autism moved from a unitary label to one that is more heterogenic, thus a spectrum of disorders that requires the understanding that individuals with autism have different needs and that their needs will change with their age and level of schooling. A brief discussion of the early service delivery models existing before the enactment of IDEA follows. The discussion includes those models most often used with children and youth identified with the autism label. To complete the chapter, a description of the changes that have occurred since the enactment of IDEA is provided.

### *Early Service Delivery Models (Pre-IDEA)*

Raymond (2012) notes that pre-IDEA, "early public special education efforts operated on a selective basis" (p. 30). Children identified with autism most often displayed significant intellectual and behavioral issues; thus, in many instances, they were educated with children demonstrating severe intellectual disability and/or serious emotional disturbance. Routinely, public schools denied access to children with autism, stating that schools did not have the capacity to meet the child's needs. Typically, the only educational options available for parents were to arrange for home schooling or to place the child in a state or private institutional setting. The result of this denial of services was that the child with autism was being educated in an inappropriate educational program in a highly restrictive residential setting with persons labelled as having severe/profound mental retardation or severe mental health issues. The denial of services by public schools is one of the injustices that Congress sought to rectify by passing IDEA in 1975.

#### *Institutional Placement*

Early institutions were seen as facilities to house individuals who had mental retardation (now intellectual disability) and/or those who were considered insane (now mental illness). In fact, when Howe and his colleagues originally planned institutions, they were called schools and were considered to be places for habilitation (Noll, Smith, & Wehmeyer, 2013). Two types of institutions were most prevalent: (1) large imposing buildings that housed numerous individuals or (2) groups of smaller buildings known as cottages. At their conception, institutions were developed to meet the needs of the patients and to allow healing or training to occur; later institutions became storehouses for persons whose disability or behaviors were unacceptable to society. Wolfensberger (1975) notes that institutions are places where inmates are isolated from family and society, where they are crowded into spaces built for fewer patients than their current population, and where higher functioning inmates are exploited as free labor to support the institution and care for those who are less able.

### *Self-contained Schools*

Post World War II, many parents of children with intellectual disability and/or autism began to question the placement of their children in institutions. Parent advocacy groups began a twofold campaign, one focus being the development of private, self-contained day schools for their children and the other a movement to expand services in the public schools so that their children could be educated with their peers. It was at this time that educational programs for students with autism began to appear, although most of these programs were not in public school settings (White et al., 2012). During these years, parents and researchers often agreed that self-contained schools would be the best option for those individuals whose "need for specialized instruction is considered so significant that a special school or other facility is considered necessary" (Mastropieri & Scruggs, 2014, p. 18). One of the most influential alliances at this time was The National Association of Parents and Friends of Mentally Retarded Children, which was founded in 1950 by a collection of parent groups and interested professionals. The organization grew and is now known as The Arc, which continues to support children and adults with intellectual disability. With the enactment of IDEA in 1975, the numbers of special day schools and other private or public facilities has declined. Mostly, the decline has been the result of the parent advocacy movement and the legislative mandate for the expansion of service options within the public school programs.

### *Self-contained Classrooms*

The first step toward moving students with disabilities into the public schools was the development of specialized classes. Students placed in self-contained classrooms, at that time, did not participate in the general education class with their peers. All content as well as support classes such as art, music, and physical education were taught separately from grade-level peers.

According to Kavale and Forness (2000), "the special class was seen as the best means for avoiding conflicts while providing universal education" (p. 280).

Although this was movement forward, many parents of children with disabilities want their children to have opportunities for interaction with their peers.

### *Later Service Delivery Models (Post-IDEA)*

Following the enactment of IDEA, the shift in service delivery is from "historical placement in large, isolated residential institutions to the more common practice in recent years of placing children in the neighborhood schools they would be attending if they had no disabilities" (Raymond, 2012, p. 30). This shift is a monumental change in the method in which students with disabilities receive services and is seen in the number of students with autism who are now being educated in general education classrooms. Heward (2009) states that now "Approximately 3 in 10 students with ASD are educated in general education classrooms, about 18% of students with ASD are served in resource rooms, 40% in separate classrooms, and 10% in separate schools or residential facilities" (p. 282).

#### *Continuum of Alternative Placements (CAP)*

With the enactment of IDEA in 1975, there came a change in educational service delivery. The primary goal according to Kavale (2002) was "to ensure educational equity and eliminate the miseducation and chronic exclusion experienced by children with disabilities" (p. 201). To do this, schools districts were required to provide a full continuum of placement options, also known as a continuum of alternative placements (CAP). The CAP model is based on a model developed by Deno in 1970, called the Cascade Model. Deno's model features an up-ended pyramid divided into seven horizontal sections, representing by size the number of students who should be provided with each type of services. The service options ranged from total immersion in the general education setting with no additional supports, to a setting in a residential or hospital setting where extensive supports are provided (Hong, Schulte, & Ivy, 2015). As the Virginia Department of Education (2011) states "using the continuum concept makes it more likely that each student will be placed appropriately in an environment that is specifically suited for him or her" (p. 26).

In later IDEA authorizations, a similar form was included in the legislation and labeled as a Continuum of Alternative Placements (CAP). The legislation mandates that all children, regardless of disability or not, be provided a free, appropriate public education (FAPE) in the least restrictive environment (LRE). The environment is to be selected from this continuum of placements or alternative settings where appropriate education programs could be designed to meet the unique needs of each child (Kavale & Forness, 2000). CAP contains placement options similar to those proposed by Deno, ranging from the most integrated, that is, general education with the student's peers, to the most segregated, that is, hospital or homebound education. However, the degree of restrictiveness of the placement is based on the needs of the individual student and not on an established view of what would be the most restrictive.

### *Pull-out Services (Self-contained and Resource Rooms)*

The first steps down on the CAP, after the general education classrooms, were two sites where students would receive some or all of their educational services: resource room and self-contained classroom. Typically, the amount of time when services are delivered outside the regular (general) classroom denotes whether the placement is considered to be a resource room or a self-contained classroom. According to Heward (2009, p. 283):

> Many students with autism spend a portion of each school day in the general education classroom with same-age peers and part of the day in a resource room where they receive intensive, specialized instruction focused on their individualized education program (IEP) goals and objectives.

When students are assigned to a resource room service delivery model, they will spend a portion of the day in the general education classroom with their peers and a designated amount of time in the resource room receiving specialized instruction in content areas or social skill development (Mastropieri & Scruggs, 2014). Those students whose needs indicate more time is required for instruction may be assigned to a self-contained class. Although the name seems to indicate that the student will spend all his/her time in the classroom away from the general education class, usually this is not the case. It typically does indicate, though, that the student will spend most of his/her time away from his/her general education peers. Even at this level of the CAP, however, students with disabilities usually "interact with their nondisabled peers during art, music, physical education, recess, lunch, and assemblies" (Mastropieri & Scruggs, 2014, p. 18).

### *Push-in Programs (Mainstreaming)*

In conjunction with the introduction of legislation such as IDEA and differing service delivery options was the introduction of a process known as "mainstreaming." Mainstreaming focused on moving students from their self-contained classes into the general education classroom. Kavale (1979, 2002) suggested that the concept of mainstreaming, or the push-in programs, was actually a reaction against the exclusive use of the special class where students continued to be segregated from their peers. That is, they were included in the school but still excluded from full participation with their peers. On the positive side, Mastropieri and Scruggs (2014) stated that advocates of mainstreaming believed that students, both those with disabilities and those without, would benefit if they all had some time in the classroom together. General education teachers espoused concerns that these students with a disability were just "visiting" the classroom at specific times during the day and that the teacher did not have full responsibility for the programming. An additional concern was the conviction by many that the student should not be allowed to participate in the general education classroom until he/she reached an "adequate" skill level; that is to say the student with autism must have earned the right to attend the general education class. In this model, a student with disabilities begins his/her educational cycle in the special classroom and if he/she progresses enough, he/she might be allowed to participate in the general education classroom; hence, the student is moved to that setting. Consequently, as Kavale (2002) states, the process of trying to gain access to the general education classroom from a special education classroom "resulted in special education becoming a place rather than a process" (p. 205).

### *Inclusive Programming*

From the opposite point of view, those who espouse inclusion, or inclusive programming, believe that all students should begin their education career in the general education classroom. Students are separated only if their unique needs are significant enough that they could not be addressed appropriately in the general education classroom. Only then would they receive some, or most, of their education outside of the general education class. According to Batten (as cited in VA DOE, 2011), "the extent of inclusion should be driven by the student's needs as determined by the educational team, not by the district's convenience" (p. 28). There continues to be an expanding view that students with autism should receive their education in the general education classroom as much as possible. The result is that data show a substantial increase in the numbers of students with autism receiving an inclusive education. According to Sansosti and Sansosti (2013, p. 229):

> data from the U.S. Department of Education reveal that participation of students with ASD in the general education curriculum for more than 80% of the day increased from 9% in 1992 to 31% in 2006, representing an increase of 244%.

But still there is controversy as to the most appropriate service delivery option for students with autism and whether general education placements should be recommended for students with autism at all (Simpson, de Boer, & Smith-Myles, 2003).

### *Early Intervention Models*

Early intervention center-based programs and family centered, home-based programs are two types of programs encouraged and supported since the 1986 IDEA reauthorization, which includes education for infants, toddlers and young children and their families in its requirements for service provision. Both program types continue to be included in the IDEA legislation. An expansion of the legislation now requires a specific family-based program plan known as the Individualized Family Service Plan (IFSP) to indicate that the focus in the child's earlier years should be family centered, not individual child or school centered. The past two decades of research indicate that "appropriately structured educational programs and management in the early years can play a significant role in enhancing functioning in later life" (Dahle, 2003, p. 66). Parents and educators focus on early intervention with the belief that it can reduce the future need for more restrictive placement and expand the probability of a successful educational future for their child (Peacock et al., 2013). The requirement for early intervention has been verified by research, so that focus continues.

IDEA also requires that the child's placement should be in the LRE. For most young children, the natural setting is the home with his/her family. Thus, according to Dahle (2003), family-centered home programs for young children with autism, or any disability, should include (a) the recognition that the child is an integral part of a family system, (b) that the family's needs, concerns, and priorities must guide any educational program, and (c) that the family must be given the opportunity to participate in their child's programming. Accordingly, Handleman and Harris (2001) state, "it is well known that parental and family involvement is critical for establishing and maintaining behavior changes by students with autism" (p. 9). In fact, parental involvement and the subsequent training as providers for their child's educational and behavioral program has been emphasized since the early 1970s, when Lovaas and his colleagues trained parents of children in their study to be co-teachers (Ingersoll & Dvortcsak, 2006). The results found that the children's success continued if they lived at home with their parents and decreased if they went to an institutional setting. Therefore, parent training to participate in the program development and implementation for children with autism continues to increase.

When looking at the history of services for children with disabilities in general and autism in particular, there has been:

> [A] steady press toward greater integration of students with disabilities. The law demands education in the LRE, but difficulties have resulted from this provision coming to be interpreted as solely the general education classroom, particularly for all students regardless of type and level of disability.
>
> (Kavale & Forness, 2000, p. 290)

This steady progress began even before the original enactment of IDEA, with its focus on the LRE (Simpson *et al.*, 2003). As we look toward the future of educational services for children with autism, it is imperative that we focus educational program and service delivery planning on the unique needs of each child and where he or she is most likely to have educational, behavioral and, eventually, life success.

## Where Do We Go From Here?

As the number of new cases of autism continues to rise, families and professionals agree that there are questions that need answers. What is, or are, the underlying cause or causes of autism? What are the most appropriate evidenced-based interventions? Which educational and behavioral programs are the most effective in addressing the unique needs of individuals with autism? What service delivery options should be we identify for future educational service delivery? How can parents and family members be more involved with their children with autism as they transition into adulthood? What we do know is that research is slowly revealing answers to these questions. For example, we know now that early intervention is critical and that some persons with autism will need support long beyond high school. Of course, the journey that began in the early 1960s with our search for how to address these intense, diverse, and sometimes overwhelming needs of the individual with autism is not over yet. The following chapters provide information to guide the provision of services from birth to adulthood, ending with the need for collaboration and teamwork.

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