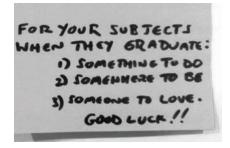
CHAPTER 1

Somewhere to Go, Something to Do, Someone to Love

Adolescents in High School and the Center on Secondary Education for Students with Autism Spectrum Disorder Comprehensive Program

> Samuel L. Odom Kara A. Hume

By the end of the first decade of 2000, adolescents with autism were enrolling in high school programs at an unprecedented rate; there was not clear guidance for how to set up a comprehensive program for those adolescents, and the young adult outcomes for these students after high school were among the poorest of any disability group. The U.S. Department of Education established the Center on Secondary Education for Students with Autism Spectrum Disorder (CSESA) to design and evaluate a comprehensive, school-based program. The Center began with a meeting of an advisory board of national leaders, autisic self-advocates, and families of adolescents with autism. At the end of the meeting, board members anonymously wrote on a Post-it Note their hopes for the research that CSESA would conduct. One board member wrote:



Occupational engagement (something to do), successful situating in context (somewhere to be), and close personal relationships (someone to love) are goals for all adolescents during the high school years and when they leave high school to enter the adult world. Although adolescents with autism spectrum disorder (ASD) will bring their unique strengths to school and postschool settings, they face challenges in meeting these stated goals. Through federal law and societal intent, public schools are charged with supporting students with autism in achieving individualized learning goals, successful participation, and transition to the adult world. The program developers designed the CSESA models to assist public school personnel in providing the necessary learning and social experiences for their students with autism to meet the young adult outcomes just noted. The purpose of this introductory chapter is to describe a broader context that has served as the basis for the development of the CSESA model.

AUTISM IN HIGH SCHOOLS

A noted psychologist stated that adolescence is a period of human development beginning in biology and ending in society (Petersen, 1988). Puberty brings changes in body form and chemistry, and cognitive abilities continue to advance toward adult functioning levels (Lerner, 1998). Interests in independence and self-direction, sexuality, and moral values become major themes of life, as do concerns about future and life transitions (e.g., attending college, getting a job) (American Academy of Child and Adolescent Psychiatry, 2010). Family relations shift as the adolescent strives for increased autonomy and parents adjust to inevitable changes in the parent–adolescent relationship (Steinberg & Morris, 2001). Peer relationships predominate (Parker, Rubin, Erath, Wojsalawowicz, & Buskirk, 2006) during this period. A comprehensive program for high school student with ASD has to be conceptually situated within typical adolescent development.

Despite great heterogeneity in development, patterns in the profiles of adolescents with ASD have emerged from several longitudinal studies (Sanford et al., 2011; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004; Taylor & Seltzer, 2010). Although parents report modest improvements in autism symptoms during adolescence (Taylor & Seltzer, 2010), difficulty with social competence and formation of social relationships continues as a limitation and challenge for the majority of adolescents with ASD (Ormand, Krauss, & Seltzer, 2004). Restricted and repetitive behaviors that emerge in early childhood often continue into adolescence (Howlin, Goode, Hutton, & Rutter, 2004). For some adolescents, externalized maladaptive behavior may become less severe (Shattuck et al., 2007), although parents still described it as a significant problem (Fong, Wilgosh, & Sobsey, 1993). Mental health conditions increase during adolescence, with depression (Ghaziuddin, Ghaziuddin, & Greden, 2002) and social anxiety (Bellini, 2006) being among the most common.

Adolescence is also a period of particularly high stress for families of individuals with ASD, as the normative challenges associated with the transition to adulthood are compounded with multiple difficulties unique to the disorder (Seltzer et al., 2010). Not surprisingly, anxiety is high for mothers of children with ASD during the adolescent period as they anticipate their child's transition from the school system and worry about the future (Lounds, Seltzer, Greenberg, & Shattuck, 2007). Beyond worries about transition, many parents of older individuals with ASD experience "burnout" from the caregiving burden (Seltzer, Floyd, Song, Greenberg, & Hong, 2011).

By most accounts, public education has not been successful in meeting the needs of adolescents and young adults with ASD. From the National Longitudinal Transition Study 2012, Lipscomb and colleagues (2017) found that relative to other students with individualized education plans (IEPs), students with ASD had significantly more trouble completing activities of daily living, had a lower sense of self-direction, had fewer planned activities and social engagement with friends, and were less likely to have had paid employment outside of school. These findings may well translate into poor outcomes in early adulthood. In their analysis of the National Longitudinal Transition Study–2 (NLTS2), the predecessor to the previously cited study, Roux, Shattuck Rast, Rava, and Anderson (2015) reported that outcomes for young adults with ASD and their families are among the worst of any disability group.

Other longitudinal studies have documented that about one-third of young adults with ASD are unemployed, and those who are employed often fail to maintain employment or struggle with employment over time (Taylor, Henninger, & Mailick, 2015). Young adults with ASD are more likely to live at home after high school and less likely to live independently, in comparison to individuals from other disability groups (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014). In her review of outcome studies for adults with ASD, Howlin (2014) reported that, on average, 48% of participants had poor to very poor outcomes. This body of research suggests a strong need for comprehensive programming at the secondary level that addresses the critical and diverse needs of autistic adolescents. This need is magnified by the estimate that in 2019 there were nearly 283,000 adolescents with autism in U.S. high schools who will be transitioning into the community in the near future (i.e., 15.3 million adolescents enrolled in public high schools (National Center for Education Statistics, 2020) × prevalence rate of 1 in 54 (Maenner, Shaw, & Baio, 2020).

IMPORTANT PROGRAM FOCI FOR HIGH SCHOOL STUDENTS WITH AUTISM

The specific learning goals of adolescents with autism are unique and, by law and best educational practice, should be individualized. However, as a group, general areas of focus for students with autism and their high school program can be discerned.

These areas include transition, as supported by school and family, academics as accessed through reading comprehension, social competence, and independence.

Transition and Families

As noted, analyses of the transition of students with ASD into work or education/training have yielded bleak results (Anderson et al., 2014; Roux, Shattuck, Rast, & Anderson, 2017). Transition opportunities are often limited by the absence of preparation for the student, difficulty adapting to new environments, and minimal supports (Roux et al., 2015). Given the characteristics associated with most youth with ASD, an effective school program must bridge learning from the school classroom into employment settings and/or postsecondary education (Roux, Rast, Garfield, Anderson, & Shattuck, 2020).

Adolescence is also a time of notably high stress for families of children with ASD; this stress, in turn, has been associated with compromised health and well-being in parents who continue to be the primary caregivers for their children well into adulthood (Seltzer et al., 2010). As autistic students leave high school, parents often assume the role of primary advocates for their adolescent children, often adding to an already stressful period. It is a role for which many parents feel unprepared. Despite this high level of stress and caregiver burden, very few services are currently offered to help these families cope with the many challenges they face or to actively support their involvement in planning for the transition out of high school. Understanding and preparing for the primary advocate role should be an important dimension of school-based programs for adolescents with autism.

Academics and Literacy

By the time students reach high school, academic content is accessed through reading and other forms of literacy. For high school students with autism, research tells us (1) the rate of reading improvement is significantly slower than that of students with other disabilities, (2) literacy comprehension that may allow access to content in other academic classes is challenging, and (3) literacy is also a functional skill for those students who have vocational outcomes (Fleury et al., 2014). Equipping adolescents with autism for the literacy-rich world that exists after high school should be a primary initiative for any comprehensive school program.

Social Competence and Peer Relationships

Peer relationships play an instrumental role in the lives of youth—not only because of the enjoyment they can bring, but also because of the important contributions they make to adolescent development, well-being, and successful transitions (Moses & Villodas, 2017). The interactions students have with one another—and

with school staff and other community members—can contribute to their social and emotional development, promote positive adjustment, and impact their engagement and involvement in school (Wentzel, 2017). Numerous descriptive and longitudinal studies indicate that social interactions and peer relationships remain especially limited for high school students with ASD (Carter, Sisco, Chung, & Stanton-Chapman, 2010). Left unaddressed, such limitations extend beyond the high school years, as evidenced by findings that the social contacts and relationships outside of the home are also quite limited for young adults who have left school (Carter et al., 2014).

Independence

For many high school students, independent performance is an essential skill for successful participation in the range of high school, vocational, and community environments (Hume, Boyd, Hamm, & Kucharczyk, 2014). A primary difficulty experienced by individuals with ASD, however, has been to participate independently and appropriately in the range of environments in their lives (Hume, Loftin, & Lantz, 2009). Without continued adult prompts, individuals with ASD may not display target skills and spontaneous responses may not generalize or continue over time (MacDuff et al., 2001). Individuals with ASD may continue to rely on the presence of an adult or treatment contingency to remain engaged or to complete activities (Lang, Tostanoski, Travers, & Todd, 2014). The removal of close supervision, adult prompting, or contingencies may lead to backsliding, such as reoccurrence of off-task behaviors or a decline in engagement and productivity across settings (Webster, 2021). Strategies for preventing or reducing the reliance on prompting from adults and increasing independence need to be high priorities for many students with autism.

DESIGNING A COMPREHENSIVE PROGRAM

For children and youth with autism, there has been a history of developing comprehensive programs to address their multidimensional learning needs (Odom, Boyd, Hall, & Hume, 2014). To date, however, such models of treatment have not been developed specifically for adolescents with ASD in public high school programs. Responding to this need, the CSESA drew from the empirical intervention work conducted with adolescents having other types of disabilities, the design-based instructional development process applied in other areas of education (Cobb, Confrey, diSessa, Lehrer, & Schauble, 2003), and the application of implementation science (Aarons, Hurlburt, & Horwitz, 2010; Albers, Mildon, Lyons, & Shlonshy, 2017; Fixsen, Blase, Metz, & Van Dyke, 2013) to support the uptake and utilization of evidence-based practice embedded within the model.

Model Development Process

The CSESA model was developed over a two-year period using elements of a design-based research approach (Fishman, Penuel, Allen, Cheng, & Sabelli, 2013). Introduced to the field of education by Ann Brown (1990) in the early 1990s, design-based research (also called "design experiments") has its origins in the field of engineering, in which researchers conduct experiments involving small features of a structure or process, altering features to determine whether such changes improve the overall structure/process under development. Design-based research, as it is applied in education, is formative in nature; that is, researchers use information about practices and students' responses to adapt, modify, or adjust instructional procedures in ways that improve feasibility, acceptability, and potentially effects on student learning (Gravemeijer & Cobb, 2013). The design research process allows flexibility in procedures and utilizes a constant feedback loop of information and data that informs the design of instructional/intervention programs (Fishman et al., 2013). In this process, we began with researcher work groups, brought in stakeholders at several points to provide feedback, conducted pilot studies of individual program components, then completed a pilot study of combinations of components (see Figure 1.1).

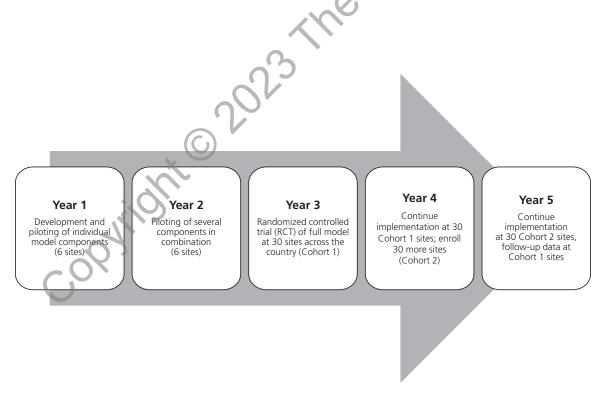


FIGURE 1.1. Timeline for CSESA activities.

Work Groups

Drawing from the broad intervention research literature, the CSESA researchers elaborated on a school-based program model originally developed by the National Professional Development Center on Autism Spectrum Disorder (NPDC). To adapt the NPDC model specifically for high school students with autism, they identified four primary areas of learning needs for most students: academics, social competence, independence and behavior, and transition and families. The first step, then, was to convene the research staff and experts who had led intervention work in each of those four areas. In most cases, previous interventions with evidence of efficacy had been developed for student having other types of disabilities but not autism (e.g., intellectual disability, learning disabilities). The initial charge to these work groups was to adapt currently efficacious intervention approaches for adolescents with disabilities.

Researchers and program staff from six university sites, as well as consultants, parents, and school staff members, formed work groups related to each proposed component area. Each work group was chaired by national leaders in intervention development in their areas: Diane Browder, Sharon Vaughn, and Colleen Reutebuch led academics; Eric Carter and Janine Stichter led social competence; Brian Boyd and Kara Hume, with consultation from Rob Horner, led independence and behavior; and David Test and Leann Smith led transition and families. The work groups completed initial adapted drafts of intervention procedures, procedural manuals, and other supporting documentation.

Focus Groups

To obtain feedback from potential stakeholders, the CSESA staff members conducted 28 focus groups located in four states (California, North Carolina, Tennessee, and Wisconsin) and involving 152 participants. Participants in focus groups were special education teachers, general education teachers, administrators, parents, and individuals with ASD. In addition, two national focus groups involving autistic individuals were held at annual meetings of the Autism Society of America. A full description of the focus group protocol, research questions, findings, and specific changes made to interventions has been reported in Hedges and colleagues (2014) and Kucharczyk and colleagues (2015). The findings resulted in numerous changes to the intervention materials (e.g., adding technology to assist staff in tracking student adaptive behavior skills, aligning lesson plan formats in the academic interventions, changing peer network orientation procedures, adjusting text sizes of literacy materials). This information was incorporated into revised component feature procedural manuals and material that CSESA researchers used in the next development phase.

Initial Pilot Studies

The interventions related to each component were revised and reoperationalized before starting the pilot studies. In these pilot studies, CSESA research staff and collaborating school personnel implemented and examined the impact of each CSESA component. The studies occurred at nine high schools located in four states. Thirty-three adolescents with ASD, 33 staff members, 28 families, and 32 peers participated in these studies. Each pilot study included multiple opportunities for data collection, weekly meetings with the implementation team to review process and outcomes, and collection and review of fidelity and/or social validity data. In most settings, a research staff member served as the primary implementer, with school staff serving in a support role. Data from these pilot studies provided additional guidance on needed revisions for each intervention. Examples of such revisions included (1) adjusting the five unit topics in the social skills curriculum to allow for application of more complex skills, (2) developing visual supports to outline the steps of the literacy intervention, (3) reducing the meeting time necessary for the independence and behavior component, and (4) providing model lessons for work-based learning.

Contrasting Features Design Pilot Study

The initial pilot studies focused on the single individual components delivered mainly by research staff. The purpose of the next phase of the development process was to examine how well the individual components worked when they were delivered (1) in combination with one other component and (2) by school staff members, with CSESA research staff providing training and coaching. Building on the logic of the Campbell and Fiske (1959) multimethod, multitrait matrix, a school team would implement two components (i.e., over a 1-school-year time period) and would alternatively serve as the control for the other components not implemented in their school but implemented in other schools. The study took place over a 1-year time period. For example, the Tennessee school would implement the social and transition components and serve as control (i.e., continue practices as usual) for the academic and independence components. All combinations of component pairs were examined. Frequent meetings involving the research and school teams and employing the framework established in previous pilot studies were key features of the design experimentation framework. The findings were that school staff members generally implemented the targeted interventions for their specific school with fidelity, with some variation across schools, and did not implement interventions that were not targeted for the schools. This information was incorporated into the final development of the CSESA model. A more detailed study description is provided by Hume and Odom (Chapter 9, this volume).

Assembling the Final CSESA Model

The culminating activities of this model development process were to complete the final revisions of each component feature, prepare a training process and materials, and establish a coaching model that would support the implementation of CSESA model in high schools. Because of the complexity of the model, the fact that it is a whole-school intervention to be implemented with the range of students on the spectrum in inclusive and noninclusive settings, the implementation of the full CSESA model was planned to occur over two school years.

Testing Implementation and Efficacy

To examine the use and effects of the CSESA program, CSESA investigators conducted a cluster randomized trial. Sixty high schools were randomly assigned to a condition in which they received training, materials, and implementation support for using the CSESA program, or a condition in which they generally provided services as usual. Outcomes for schools, in terms of program quality, and students (i.e., for goal attainment and standardized measures) were collected at the beginning and end of the study. In addition, implementation measures were collected in both CSESA and service-as-usual (SAU) schools. The findings from these studies are reported by Hume and Odom (Chapter 9, this volume).

THE CSESA MODEL

The CSESA investigators made several assumptions early in the development process. First, because high school students with ASD have a wide range of abilities, CSESA investigators made the decision to establish a model that would be appropriate for students with higher and lower support needs (e.g., students with intellectual disability participating in special education classes for most of their day to students enrolled in general education classes and likely to receive a regular diploma). Second, from the literature, the CSESA investigators identified the high-need areas for high school students with autism as academics (Fleury et al., 2014), social competence (Carter et al., 2014), independence and behaviors that limited independence (Hume et al., 2014), and transition/families (Test, Smith, & Carter, 2014).

The CSESA Process

The process that the CSESA model followed appears in Figure 1.2 and detailed information about the process and broader implementation factors appears in Hall, Steinbrenner, Kucharczyk, and Perkins (Chapter 8, this volume). Once the

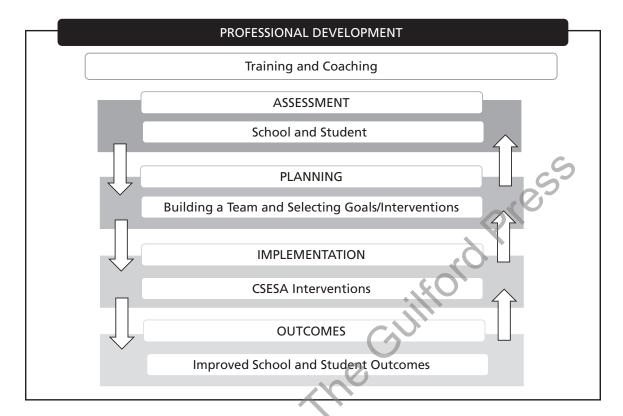


FIGURE 1.2 CSESA process.

school system (broader organizational context) makes the decision to adopt the CSESA model, the initial step in this adoption is professional development, which begins with the school's district or school staff, sometimes called coaches, who will be supporting the model implementation. When trained, the coaches provide orientation, training, and ongoing coaching support for school personnel. In this initial period, the school forms a collaborative team, which we called the A(Autism)-Team (discussed more in Odom, Chapter 2, and Hall et al., Chapter 8, this volume). The second part of the CSESA model is assessment of the school program environment, using the Autism Program Environment Rating Scale— Middle/High School (APERS-MH), and assessment of individual students using the Secondary School Success Checklist (SSSC; Hume et al., 2018). The assessment provide information necessary for planning, improving program quality, and designing measurable and observable student goals. The student goals inform the decision about the interventions in which individual students will participate and implementation (again, described more fully in Hall et al., Chapter 8, this volume). Last, outcomes for individuals on their goal attainment and on the school's program development conclude the process.

CSESA Foundation, Domains, and Components

CSESA is designed to support all the students with autism in a high school, and the breadth of the learning needs for those autistic students is broad. So, by necessity, the CSESA program is broad with a lot of "moving parts" (Figure 1.3). The foundation of the program is a set of practices, described by Odom (Chapter 2, this volume) that serve as base context necessary for the CSESA program to operate.

We have organized the contents of the CSESA program in multiple domains, noted earlier, which the research, school personnel, families, and students have told us are important. The domains are the conceptual groupings of intervention and practices that make up the CSESA program. The domains are Transition and Family, Academics, Social, and Independence. For the Transition and Family domain, there are four in-school/community interventions and one family intervention program. The in-school/community interventions are community and school resource mapping, transition planning, student involvement in IEP and individualized transition plan (ITP) processes, and work-based learning (described in detail in Kraemer, McDaniel, Fowler, & Regan, Chapter 3, this volume). The intervention program that focused specifically on families was Transitioning Together, which prepared families for their child's transition out of school

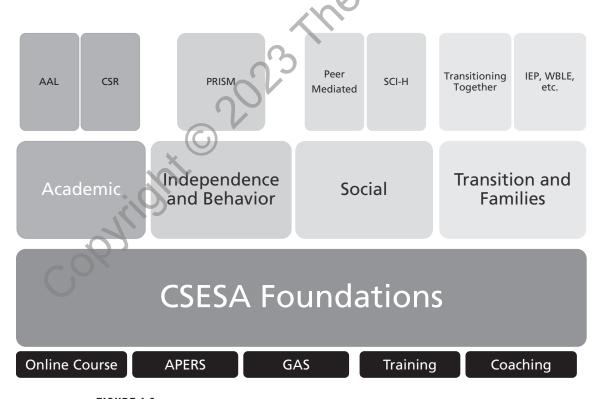


FIGURE 1.3. CSESA foundation, domains, interventions, and practices.

and into the world of work and community is described in DaWalt & Szidon, Chapter 7, this volume). For the Academic Domain (Brum, Hall, & Stichter, Chapter 4, this volume), a literacy intervention that focuses on comprehension, Collaborative Strategic Reading—High School (CSR) was adapted for autistic adolescents who had some initial reading skills (i.e., at the second-grade level) but were challenged to understand the content typically delivered in high schools. For students with autism who lacked any reading skills, the Alternative Achievement Literacy was adapted. The Social Domain included three interventions (Steinbrenner, Hall, Carter, & Stichter, Chapter 5, this volume). For students with ASD who had fluent communication skills and could benefit from a group-based approach, the Social Competence Intervention (SCI) addressed goals of emotional literacy, problem solving, and behavioral regulation. For all students, a second set of interventions/ practices was peer-based. The peer-mediated interventions comprised formation of peer-social network groups that enhanced social engagement and peer-support practices in which peers facilitated more specific learning objectives of individual students with autism. The fourth domain focused on independence and behavior. In the Independence and Behavior domain (see Hume, Kucharczyk, Retschler, & Boyd, Chapter 6, this volume), the assessment information from the SSSC and subsequent goal developed for individual students was used to link the goals to a set of evidence-based practices identified as most relevant for students in high schools and to foster their use for teachers. An emphasis on self-management practices for students with autism was also a focus in this domain.

SUMMARY

In this chapter, we have provided an overview of the CSESA comprehensive program for student with autism in high schools. We have highlighted the convergence of factors related to autism, adolescence, and the high school environment as a perfect storm of complexity that affects overall program quality and the quality of the individual program that students with autism receive. For many of these students, we propose that four domains of emphasis are important: Transition and Families, Academics, Peer and Social Competence, and Personal Independence and Behavior. The CSESA program contains specific component interventions and practices that address each of these domains. Authors in the subsequent chapters of this volume address the foundational component practices necessary in a CSESA high school, component interventions and practices for each domain, and procedures for implementing the CSESA programs (Hall et al., Chapter 8). In the concluding chapter, Hume and Odom (Chapter 9) review the research conducted with the CSESA model, as well as resources generated by CSESA that are available in Appendix 9.1 or on the CSESA website (https://csesa.fpg.unc.edu).

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