Physical Disabilities: Education and Related Services



Physical Disabilities: Education and Related Services, 2018, 37(2), 1-12.

doi: 10.14434/pders.v37i2.24881

© Division for Physical, Health and Multiple Disabilities



ISSN: 2372-451X

http://scholarworks.iu.edu/journals/index.php/pders/index

Article

STRATEGIES TO INCLUDE STUDENTS WITH SEVERE/MULTIPLE DISABILITIES WITHIN THE GENERAL EDUCATION CLASSROOM

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Abstact: Federal legislation such as IDEA (1997) and NCLB (2001) have led to an increase in the number of students with significant disabilities receiving instruction in the general education classroom. This inclusionary movement has established a more diverse student population in which general and special education teachers are responsible for providing instruction that meets the needs of all their students. Although most research focuses on effective inclusionary practices for students with high incidence disabilities (e.g., learning disabilities), literature has revealed a dramatic increase in the number of students with severe/multiple disabilities receiving support in general education settings. Therefore, it is imperative that educators acquire the effective inclusive practices necessary to meet the unique needs of students with severe/multiple disabilities. A review of literature was conducted to determine effective ways to include and support students with severe/multiple disabilities within the general education classroom.

Keywords: *inclusion*; *severe disabilities*; *multiple disabilities*

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Introduction

The National Center for Educational Statistics (2016) found that there were 132,000 children with multiple disabilities between the ages 3 and 21 being served in federally supported educational programs in the 2013-2014 school year. Individuals with multiple disabilities, which refers to persons with concomitant impairments (e.g., intellectual disability and blindness, intellectual disability and orthopedic impairment), usually need support in major life activities that include domestic, leisure, community access, and vocational programming. Often these students receive educational services in separate special education classrooms and do not have the opportunity to be fully and effectively included with their nondisabled peers. However, the Individuals with Disabilities Education Act (IDEA, 2004) and No Child Left Behind (NCLB, 2002) have led to an increase of students with severe/multiple disabilities receiving instruction in general education settings.

The provisions of NCLB (2002) created another push towards inclusion by requiring high-quality state standards and assessments (U.S. Department of Education, 2009). The NCLB specifically emphasized teacher accountability and high student achievement (Birman, Desimone, Porter, & Garet, 2000) based on the performance of all students on state standardized testing on the general education curriculum. Additionally, NCLB mandated the following: (1) students with disabilities must be included in state assessments, and (2) assessment scores for all students must be calculated in the school district's annual yearly progress (Code of Federal Regulations, 2006). The accountability mandates of IDEA (2004) and NCLB have led to a focus on inclusive education to ensure that all students are receiving instruction in the general education curriculum (Harvey, Yssel, Bauserman, & Merbler, 2010).

Including students with disabilities in the general education classroom has been a goal of education reformists for numerous years. IDEA (2004) and NCLB (2002) emphasized that students with disabilities should have access to and demonstrate academic progress in the general education curriculum. To meet the requirements under IDEA and NCLB, educators must be prepared to meet the needs of students with varying abilities in an inclusionary classroom environment. However, the central focus of previous traditional teacher preparation in special education has been on planning instruction and making instructional adaptations for students with disabilities in non-inclusionary environments. Yet, it is only recently that the focus of these procedures has been the inclusive classroom (Cook, Cameron, & Tankersley, 2007). High quality state standards and assessment, in concert with "highly qualified" teacher requirements, have transformed teacher education programs. Nationwide, prospective special education teachers are required to obtain certification in special education and certification in the content area they will be instructing.

IDEA (2004), in alignment with NCLB (2002), calls for *highly qualified* teachers for students in the K-12 school system. This term describes specific standards set for all teachers and includes gaining "full state certification as a teacher" and successful completion of a "state teacher licensing examination." Hence, local educational agencies are required to ensure that all teachers are highly qualified in the content areas in which they teach and that students with disabilities be taught by highly qualified special education teachers (Code of Federal Regulations, 2006). These federal requirements have impacted teacher licensure and certification testing.

History of Inclusion

In 1975, Congress passed the Education for All Handicapped Children Act (U.S. Bureau of Education), which was later reauthorized to IDEA (1990), establishing a federal mandate that all students with disabilities would receive a free and appropriate public education in the least restrictive environment (LRE). One purpose of IDEA was to include students with disabilities into the educational system who had previously been excluded (National Council on Disability, 1994). According to the Code of Federal Regulations (2006), LRE focuses on including students with disabilities in a general education setting "to the maximum extent appropriate and to ensure that children with disabilities...are educated with children who are nondisabled" (34 CFR 300.114). The U.S. Department of Education stated IDEA presumes that the first placement option considered for each child with a disability is the regular classroom in the school that the child would attend if not disabled, with appropriate supplementary aids and services to facilitate such placement (Code of Federal Regulations, 2006). Thus, before a child with a disability can be placed outside the regular education environment, the individualized education program (IEP) team must consider the full range of supplementary aids and services that could be provided to facilitate the child's placement in the regular classroom setting.

Inclusion in Public Education

IDEA (2004) and NCLB (2002) focused on providing students with disabilities access to the general education curriculum in a LRE. In accordance with LRE, students with disabilities need to be educated with non-disabled peers and placements outside the general education classroom should only be considered when supplemental aids and related services do not provide an appropriate education in a general education classroom.

These federal laws have resulted in a higher percentage of students with disabilities receiving their instruction in a general education classroom. Although most of the research on inclusion has focused on students with high incidence disabilities, literature has revealed a dramatic increase of students with severe/multiple disabilities receiving support in general education settings (Sailor, Gee, & Karasoff, 2000).

Not only have these federal laws increased the number of students with low incidence disabilities in inclusive settings, research also indicates multiple social and academic benefits from inclusion. The social benefits for students with severe/multiple disabilities include social acceptance, increased self-esteem, and improved social skills (Kliewer & Biklen, 2001; Mu, Siegel, & Allinder, 2000). A two-year longitudinal study compared the growth of social competence of 40 students with multiple disabilities (Fisher & Meyer, 2002). Half the students received instruction in an inclusive environment and the other half were instructed in a self-contained classroom. After a two-year period, students receiving services in a general education setting scored significantly higher on the Assessment of Social Competence.

In addition to gains in the social and emotional domains, students with severe disabilities have also improved academically. Falvey (2004) stated, "As a result of a comprehensive review of the extant literature by myself and my colleagues, we were unable to identify even a single research article that found that segregated service delivery models are more effective than integrated

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models for students with severe disabilities" (p. 10). Research has also indicated that elementary students improved by 31.7% in mathematics and middle school students academically increased in mathematics by 12.5% and increased in reading by 13.8% (Teigland, 2009).

This inclusionary movement has established a more diverse student population in today's classrooms. General educators and special education teachers are responsible for providing an education that meets the needs of all their students. Therefore, educators need to acquire the knowledge and skills necessary to meet the ever-changing classroom population (Jenkins & Ornelles, 2007).

Instructional Practices

A meaningful and accessible inclusive education for students with severe/multiple disabilities consists of appropriate accommodations and/or modifications that allow students to gain access to the general education curriculum (Agran, Brown, Hughs, Quirk, & Ryndak, 2014). Browder and Spooner (2011) defined general curriculum access as providing grade-aligned academic instruction for students with disabilities. To establish curriculum accessibility, The National Center on Educational Restructuring and Inclusion (NCERI) identified six effective instructional practices in inclusive classrooms: multi-level instruction, cooperative learning, activity-based learning, mastery learning, technology, and peer support. Proponents of effective instructional strategies address similar practices as those identified by NCERI but also note differing evidence-based practices in inclusionary settings. A strategic principle, known as Universal Design for Learning (for more information visit CAST at http://www.cast.org/), has been adopted in many inclusionary classrooms since it addresses the core principles of NCLB (2002) and NCERI.

The principles of Universal Design for Learning (UDL) are anchored in the following evidence-based practices: explicit instruction, differentiated instruction, peer mediated instruction, curriculum-based evaluation, and assistive technology (CAST). UDL is founded on the premise that effective instructional practices are *built-in* and proactive to accommodate the widest range of all learners, including students with severe/multiple disabilities (Scott, McGuire, & Embry, 2002; Scott, McGuire, & Foley, 2003). Additionally, UDL is used to develop and implement assistive technology and instructional accommodations and modifications to support curricular accessibility, align student's IEP goals with the core curriculum, and support student progress (Janney & Snell, 2006; Wehmeyer, 2006).

Evidence-Based Practices

A systematic review of literature was conducted to determine the most effective ways to include students with severe/multiple disabilities within the general education classroom. An electronic database search was conducted utilizing EBSCO Host to determine evidence-based practices for inclusion of students with severe/multiple disabilities. Although, there is a lack of research with this unique population, certain themes to effectively include these students emerged. These themes included the proper use of augmentative and alternative communication devices, use of micro-switches, embedded instruction, wait time, and utilizing appropriate specialized

instruction during inclusion. Using these evidence based practices can help children with severe/multiple disabilities to be meaningfully included within the general education classroom.

Use of Augmentative and Alternative Communication (AAC) Devices

Communication skills are affected by sensory, motor, cognitive, and social capacities; and impairments in any of these developmental skill areas may interfere with communication development and socialization within the classroom (Rowland, 2011). Learners with severe/multiple disabilities demonstrate various abilities, but they share the need for extensive and ongoing supports to participate in home, school, and community activities (Siegel-Causey & Bashinski, 1997).

The term AAC refers to the compilation of methods and technologies designed to supplement spoken communication for people with limited spoken speech skills (Wilkinson & Hennig, 2007). AAC instruction is naturally embedded within the child's daily routines, which increases the likelihood that students acquire and generalize communication skills (Hourcade, Pilotte, West, & Parette, 2004). AAC is not just an output channel, but is utilized as the medium for both expressive and receptive communication (Romski & Sevcik, 1996). Studies have shown AAC devices to be a success in inclusive settings and include the importance of team strategies to reinforce the use of AAC devices throughout daily routines (Hunt, Soto, Maier, Liboiron, & Bae, 2004; Stoner, Beck, Bock, Hickey, Kosuwan, & Thompson, 2006). Chung and Carter (2013) found AAC devices to be most beneficial during inclusionary practices when the paraprofessional working with the child is trained on the device in order to encourage device use in interactions with their peers.

Chung, Carter, and Sisco (2012) reviewed literature on promoting relationships for students with severe disabilities and of the 31 studies reviewed it was found that students increased positive interactions in various inclusive settings when people within their environment were trained on the communication devices. When AAC devices are utilized using teaming and trained professionals, social interactions within the classroom can be increased and students with severe/multiple disabilities can be an active participant within classroom routines for both academics and social interactions.

Use of Micro-Switches

Micro-switch interventions have been found useful when working with students with disabilities. Micro-switches are technical devices that people with multiple disabilities might use to control environmental events with simple responses (Crawford & Schuster, 1993; Lancioni, O'Reilly, Oliva, Singh, & Coppa, 2002; Mechling, 2006). Micro-switch interventions have been used for tasks such as choice making and meaningful communication between the student and people in his or her environment. Lancioni and colleagues (2016) found that micro-switches could be effectively utilized with students that have minimal responses such as movement of eyelids. It was found that micro-switches could be adapted to help these students reach relevant goals and be included within various environments. Micro-switches can give students with severe/multiple disabilities the opportunity to be constructively engaged within the general education classroom by using simple responses in social situations as well as academic tasks.

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Embedded Instruction

Embedded instruction can be utilized to support students with moderate to severe disabilities in general education classes. In embedded instruction, students are taught skills within the ongoing routines of the general education classroom (Risen, McDonnell, Johnson, Polychronis, & Jameson, 2003) which does not cause disruption to the natural flow of the class. During embedded instruction, the classroom teacher systematically controls the presentation of instructional examples and implements instructional procedures designed to support the student's acquisition of the target skill (McDonnell, Johnson, Polychronis, & Risen, 2002). This instruction can support the student's goals in the IEP by focusing on target skills throughout daily lessons.

Students with severe/multiple disabilities often need several learning trials embedded within an activity to ensure learning and progress within the activity. Embedded instruction allows for multiple trials of the skill throughout natural routines rather than all at once within the context of the subject. Paraprofessionals are often able to build in embedded instruction procedures during general education classes without disruption to the class when properly trained. Shepis and colleagues (2001) found that improvements to the quality of instruction provided by support staff paralleled an increase in students' performance. Training support staff can occur through modeling and should be done immediately to aid in proper inclusionary practices. When embedded instruction is utilized in general education classrooms for students with severe/multiple disabilities, it can accommodate their unique learning needs and the characteristics of instructional targets (McDonnell et al., 2006).

Wait Time

It often takes individuals with severe/multiple disabilities longer to interpret what is being asked of them and they need more time to respond (Johnson & Parker, 2013). Wait time is defined as the duration between the teacher's instruction and the student's response (Tincani & Crozier, 2008) and is found to be an intervention that has very strong evidence of its effectiveness (Browder, Delzell, Spooner, Mims, & Baker, 2009; Johnson & Parker, 2013). Wait time was first established as an instructional practice in 1972 when studies found that the average wait time following a question before prompting in a classroom rarely exceeded 1.5 seconds (Rudd, 2001). Students with severe/multiple disabilities often have physical or communication difficulties making it impossible to respond this quickly to requests.

The procedure of wait time can be utilized to guarantee that students have time to process what is being asked, formulate a response, and execute a response prior to being prompted (Johnson & Parker, 2013). Prompting too soon does not allow time for students to process what is being asked and therefore, can lead to learned helplessness. Wait time procedures are often utilized when working with students with severe/multiple disabilities because it is minimally intrusive. Teachers and paraprofessionals can be easily trained on wait time procedures to aid in inclusion of students with severe/multiple disabilities. Watson (2018) identified wait time as being a key practice for full inclusion of students with disabilities. Utilizing wait time while using picture response cards was found to be successful in increasing student accuracy for students with intellectual disabilities (Clarke, Haydon, Bauer, & Epperly, 2015). Wait time procedures can be

utilized in teaching students of various ages with various disabilities (Daugherty, Grisham-Brown, & Hemmeter, 2001).

Specialized Designed Instruction

Utilizing appropriate accommodations and modifications can aid students with severe/multiple disabilities access to the general curriculum at grade appropriate levels alongside their peers. The most effective adaptations in the general classroom are using prior knowledge to develop new skills, adjusting content to make instruction concrete and relevant to the student's life (Jenkinson, 2000), and identifying the students preferred learning style (Udvari-Solner & Thousand, 1997). Modifications can be made throughout the classroom routines to ensure students are fully engaged. Some examples are modifying technology to ensure accessibility; students with multiple disabilities could use the same materials as the rest of the class but complete only a proportion of learning tasks or exercises (Jenkinson, 2000).

Use of specialized curriculum may be necessary for students with severe disabilities to be fully included in the general education classroom. It is imperative for educational teams to work together to develop a meaningful and individualized curriculum for each child to meet their unique needs (Horn, Lieber, Sandall, Schwartz, & Worley, 2002). Once a specialized curriculum is developed there should still be flexibility and the ability to adapt based on the student's day to day medical, educational, and social needs (Vrasmas, 2014). Utilizing the right adaptations, modifications, and curriculum can greatly benefit students with severe/multiple disabilities within the general education classroom.

Conclusion

Federal legislation (i.e., IDEA and NCLB) has led to contemporary educational practices for students with severe/multiple disabilities (Olson, Leko & Roberts, 2016). In 1997, IDEA defined the general education curriculum as "the same curriculum for nondisabled children." IDEA revisions in 2004 specified that all students, regardless of their abilities, have access to grade-level content, participate in state assessments, and have individualized education programs identifying how students will participate and progress in their grade-level curriculum.

Current studies regarding evidence-based inclusive practices for students with severe disabilities are emerging. Findings in the literature demonstrate that students with severe/multiple disabilities have access to a meaningful and appropriate inclusive education through IEP-specified accommodations and modifications incorporated through a UDL environment. Utilizing the above practices and materials can aid children with severe/multiple disabilities to be meaningfully included with their typically developing peers within the general education classroom. These inclusionary practices can potentially give students with severe disabilities the ability to build relationships that extend beyond the classroom and into the community.

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Physical Disabilities: Education and Related Services, 2018, 37(2), 13-33.

doi: 10.14434/pders.v37i2.25738

© Division for Physical, Health and Multiple Disabilities



ISSN: 2372-451X

http://scholarworks.iu.edu/journals/index.php/pders/index

Article

BUILDING AN INCLUSIVE POST-SECONDARY EDUCATION PROGRAM FOR YOUNG ADULTS WITH INTELLECTUAL DEVELOPMENTAL DISABILITY

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> Abstract: Since the reauthorization of The Higher Education Opportunity Act (HEOA) in 2008, postsecondary programs that include individuals with intellectual developmental disability have seen a phenomenal increase. In 2015, a National Coordinating Center along with 52 Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) were created and funded through the U.S. Department of Education's Office of Postsecondary Education. Currently, 267 programs are listed on the National Coordinating Center's website. This is an increase in programs by 500% compared to the number in 2008. As more programs are created with many of them being grass roots initiatives, a basic framework to beginning and supporting these endeavors has been identified. The purpose of this article is to provide a framework to assist those interested in beginning their own inclusive program at an institution of higher education for students with intellectual developmental disability.

> **Keywords:** postsecondary education; inclusive college opportunities; intellectual disability; transition; developmental disability

Introduction

College campuses across the United States are becoming more diverse and seeing an increase of first generation students. This increase could be related to the ever changing and competitive workforce. To better prepare employers, preliminary research seeks to understand how to better support those from underrepresented groups (Lozano & Escrich, 2017; Storlie, Mostade, & Duenyas, 2016). In one specific study, Storlie, et al. used qualitative methods to examine the career development of first-generation Latina students. The participants in the study described themselves as "cultural trailblazers." This description was used because they did not adhere to past cultural traditions and were the first to break family and cultural traditions of going to college and pursuing a different type of career. Similar to the findings from Storlie et al., it can be argued that many of our young adults with intellectual developmental disability can be called "cultural trailblazers." They are not necessarily breaking a family tradition; however, they are breaking the cultural barrier that always said young adults with intellectual developmental disability could not go to college.

Due to the past barriers, many staggering statistics on employment can be found. In fact, in 2016, the employment rate of individuals with a disability was 17.9% while the rate of those without a disability was much higher at 65.3% (Bureau of Labor Statistics, 2017). The unemployment rate of those with a disability was 10.5% while the rate of those without a disability was half that at 4.6%. One of the most startling statistics is that 34% of individuals with a disability are employed part time versus 18% for those without a disability. Greater differences in employment exist within categories of disability. In the past, this workforce neglected to include individuals with intellectual developmental disability are employed and of that 15%, just over half are earning less than minimum wage (Anderson, Larson, Wuorio, & Lakin, 2011). In addition, the competitive employment rate for young adults with autism can be as low as 4% with a majority working in sheltered workshops (Taylor & Selzer, 2011).

While employment statistics are grim for individuals with disabilities, the Bureau of Labor Statistics found that between both groups (i.e., those with and without a disability), individuals with higher levels of education are employed at higher rates than those with less education (Bureau of Labor Statistics, 2015a). Also, data show unemployment rates are lower the more education one has attained (Bureau of Labor Statistics, 2015b). These findings are not new. Over time, higher levels of educational attainment have presented higher employment rates and lower unemployment rates. Often, college is associated with a brighter future, primarily centered around employment. Many young people every year graduate high schools and land on college campuses looking for further education to prepare them for future careers. Until recently, even though data have supported improved employment rates for individuals with intellectual developmental disability with higher levels of education, college attendance was not an option for the vast majority of individuals with intellectual developmental disability. Additional postsecondary education (PSE) opportunities are needed for young adults with intellectual developmental disability to prepare them more effectively for future careers.

To address the need for PSE, the number of colleges and universities that are creating programs to help support those with intellectual developmental disability has increased by 500% over the

past 10 years. The National Coordinating Center (www.thinkcollege.net) shows there were only 49 PSE programs for students with intellectual developmental disability in existence in the United States in 2008 and now there are 267 college programs. With the reauthorization of the Higher Education Opportunity Act (HEOA) of 2008 a number of important revisions (e.g., access to financial aid, eligibility for work study) were added to allow young adults with intellectual developmental disability to have better access to the PSE environment (Higher Education Opportunity Act, 2008). In addition to students being eligible for financial aid and work study, the HEOA also allowed for the establishment of a National Coordinating Center and, thus far, 52 Transition and Postsecondary Education Programs for Students with Intellectual Disabilities (TPSIDs). Both the National Coordinating Center and the TPSIDs were funded in 2010 and 2015 (i.e., 27 TPSIDs in 2010; 25 TPSIDs in 2015). Of the 52 awards, five of the recipients received the award during both funding cycles. Many of the 47 two- and four-year PSE programs funded have assisted other programs across their state with startup funds. For example, on the *thinkcollege.net* site, it shows that five 2015 grantees created consortiums across the state. These consortiums have extended efforts and options across the states.

Not only have the TPSID programs helped increase the number of opportunities, they have also help to pave the path in research and innovation for the entire field of PSE for students with intellectual developmental disability. These additions allow faculty to conduct research across many areas. Research has been done in technology, academics, and peer mentorships. Studies focused on technology have included topics such as navigation paired with visual prompts (Kelley, Test, & Cooke, 2013), augmented reality paired with prompts (Smith, Cihak, Kim, McMahon, & Wright, 2017), and the use of mobile applications, or apps (McMahon, Cihak, Gibbons, Fussell, & Mathison, 2013). Studies on academic needs within PSE programs has increased with specific explorations of note-taking instruction strategies and strategies to teach specific academic content vocabulary (Reed, Hallett, & Rimel, 2016; McMahon, Cihak, Wright, & Bell, 2016). The use of peer supports has been suggested as an important component for successful transitions (Biggs & Carter, 2015) however, little research is available on how to effectively include peer mentors into PSE programs. The Western Carolina UP Program has provided an effective example of support roles, recruiting efforts, training, and evaluation of both paid and unpaid natural supports (Kelley & Westling, 2013).

According to the National Coordination Center, TPSID research demonstrated an increase in academic access, career development and employment, self-determination, and campus membership for participating TPSID students. In the 2014-2015 TPSID annual report, TPSIDs reported 784 students attended 5775 college or university courses; just under half were inclusive courses continuing the trend in academic access (Grigal, Hart, Smith, Domin, & Weir, 2017). The annual report also found that nearly all TPSID programs offered a credential that was conferred by the Institute of Higher Education, the TPSID program, or by a partnering local education agency based on recognized standards. In year five of the TPSID program (2014-2015), the national coordinating center reported nearly 75% of students participated in career development activities and 39% of students held paid employment. Most important, the percentage of TPSID students employed was similar to the percentage of typical college students employed. Campus membership has also increased in that TPSID data showed the majority of students participated in campus events. Students demonstrated increased self-determination

through the use of person centered planning where they took an active part in, often times leading, the planning of their college experience.

The continuing development of PSE programs has created a need for shared experiential information. Those in the beginning stages may benefit from the experiences of those who have already begun the process. The authors of this paper have experienced frequent requests to share their experiences when creating programs. The purpose of this paper is to provide a step-by-step start up framework to building an inclusive PSE program for young adults with intellectual developmental disability (Figure 1). This framework is based on the experiences of the authors in beginning or assisting in the beginning of four PSE programs at different universities and regions in the United States. This is meant as a suggested framework and the authors acknowledge that all steps may not apply to a specific situation and that other situations may require additional steps. Finally, it is suggested that this framework only be used as a quick guide for application as needed. The framework is divided into the three parts of (a) understanding the philosophical foundations, (b) program design, and (c) getting off the ground. Within each part there are a number of suggested tasks that will be important to consider and/or complete.

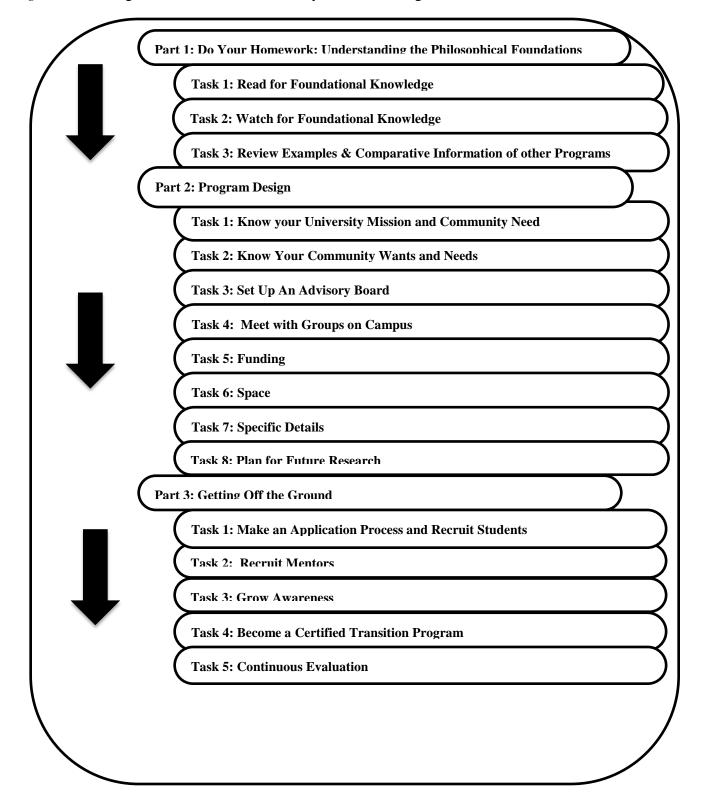
Part 1: Do Your Homework: Understanding the Philosophical Foundations

Task 1: Read for Foundational Knowledge

When considering starting a PSE, it is important to understand the philosophical foundations and historical work supporting these programs. Your first task will be to thoroughly explore *thinkcollege.net*. Think College at the Institute for Community Inclusion, University of Massachusetts Boston, serves as the National Coordinating Center for PSE programs for students with intellectual developmental disability in the United States. As part of their federally funded mission, Think College warehouses most of the philosophical and historical information you will need to consider in the initial stages of planning. They provide publications; training materials; and access to past, current, and future topics in post-secondary education. Think College will not only be a resource for you, but it will also be a resource that you can provide to teachers, transition specialists, families, and peers. By subscribing to the Think College mailing list, you will be informed of upcoming events and webinars. This is your first step.

Second, in addition to the current and latest research, you will want to read the following: (a) Hart, Grigal, and Weir (2010); (b) Grigal and Hart (2010a); (c) Grigal and Hart (2010b); and (d) Thompson, Weir, and Ashmore (2011). These readings not only provide an in-depth analysis of PSE but these selections also set the tone for why college is important and beneficial for students with intellectual developmental disability. As you delve into the research, you will begin to see that programs are highly varied and that PSE programs typically fit into three categories: (a) mixed/hybrid model, (b) substantially separate model, or (c) inclusive individual support model (Hart, Grigal, Sax, Martinez, & Will, 2006). Before you take action steps to plan, it is important for you to identify the alignment of your philosophy with the type of program you plan to create.

Figure 1. Building an Inclusive Post-Secondary Education Program



Task 2: Watch for Foundational Knowledge

In addition to the great readings, there are a few webinars that will give you a closer look at the excitement of starting a PSE program. *Rethinking College: The Film*, produced by Think College (2014), provides a 26-minute snapshot into the benefits of PSE programs. Another film is *Getting Started: Developing Inclusive College Opportunities for Students with Intellectual Disabilities* by Giffin and Papay (2012). Also browse YouTube for other great videos that have been posted from current PSE programs. These independent videos range from focusing on inspiration to information surrounding PSE programs and should be viewed with that in mind.

Task 3: Review Examples and Comparative Information of other Programs

As stated earlier, there are currently 267 programs across the country (Think College, 2017). All of the programs on the Think College website are searchable. Browse through several examples and read about specific details of each program. These programs are as varied as the university systems with which they are affiliated. All colleges are different; for example, you will not find marine biology research focus at a school located in the desert. Colleges have different missions, different programs, some are private, and some are public. You may review programs or colleges that are similar to yours and/or you may look at a variety of programs that have been established. The more programs you review, the more knowledgeable you will become when it is time to design your own program. You may find that you like and dislike some aspects of many programs.

One last reading provides a monograph of five program profiles. This monograph (found at https://thinkcollege.net/sites/default/files/files/resources/site%20visit%20monograph_final_web.pdf) provides a more detailed description of selected programs in regards to academic access, campus membership, inclusive higher education, career development, and self-determination (Weir, Grigal, Hart, & Boyle, 2013). In addition, Think College has many webinars comparing programs and other useful resources available at https://thinkcollege.net/tc-events-upcoming.

By doing a thorough review from the start you can take the bits and pieces of what you like to create one that is unique to your university/college setting. Some example programs that the authors have collaborated with can be found in Table 1. It is important to note that the programs in Table 1 are all at various points of progress with some in infant stages while others are fully developed programs and have or are currently TPSID funded.

Part 2: Program Design

Now that you have the philosophical foundation, it is time to consider your program design. Before you can plan your program, it is important to triangulate all of the information that you have read and compare that to your community needs and resources. Remember that the main outcome of your program is to build a meaningful credential, degree, and/or certificate that all graduates earn. Papay and Griffin (2013) suggested we (a) understand and document the need, (b) work with a range of stakeholders, (c) learn from model programs, (d) develop a shared vision, and (e) make a pitch. Though the following tasks are not necessarily in the same order as suggested by Papay and Griffin, the reader should see the relationship to their suggestions and to

Table 1

Example Programs

Program Name (TPSID funded)	University	Location	Website
Project F.O.C.U.S (No TPSID)	The University of Nevada, Las Vegas	Las Vegas, NV	http://www.unlvcoe.org/focus
Path to Independence (No TPSID)	The University of Nevada, Reno	Reno, NV	http://www.unr.edu/nced/projects/nced_p2i
Up Program (TPSID 2010)	The Western Carolina University	Cullowhee, NC	http://www.wcu.edu/learn/departments- schools-colleges/ceap/stl/special-education- programs/university-participant-up- program/index.aspx
Inclusive Education Services (TPSID 2015)	The University of Central Florida	Orlando, FL	http://ies.sdes.ucf.edu/
CarolinaLIFE (No TPSID)	The University of South Carolina	Columbia, SC	http://www.sc.edu/study/colleges_schools/ed ucation/partnerships_outreach/carolinalife/ind ex.php

the ultimate goal to develop a shared vision with key stakeholders. One of the most important things is to have a "sales" pitch. What is your elevator speech (Gelb, Nord, Migliore, & Butterworth, 2012) about your program? Most often used in supported employment settings, an elevator speech is a brief pitch that summarizes what your program does, who it serves, and what you need. It should be deliverable in 20-30 seconds. This pitch will be refined as you design the program, but the initial pitch is essential to craft during the beginning stages. Therefore, establishing your philosophical foundation is critical to do as a first step. You will need to identify the core components of your program and then you will need to sell this program to others. It needs to be broad enough and have limited jargon so that it is understood by students, families, university personnel, and community members. The pitch may need to be tailored to the audience. For example, when trying to recruit volunteers you will want to include not only what the program is but also what the benefits are to volunteering. On the other hand, if you are pitching the program to university administrators, you will need to discuss the needs, how it can be successful, and the research currently published on similar programs. This is especially important when taking time to master Part 1 of these suggested steps. The authors of this piece have given their elevator speech at least 100 times in the past year and will continue to do so every time someone says 'tell me about your program.'

Task 1: Know your University Mission and Community Need

What is the mission at your college or university? Many people may work at a university for years and never know the mission. In the design process, this is a critical first step to establishing a PSE program at your school. Your program must fit into the college mission as a whole. In fact, this could be part of your sales pitch and could later be worked into your program's mission statement. Once you read your university's mission, you will see that it is inclusive to all students including students with intellectual developmental disability. The authors have yet to read a university mission that is not inclusive to everyone.

Task 2: Know Your Community Wants and Needs

The next task in Phase 2 is to know your community wants and needs. Programs should not be developed without examining one's own community culture. It is important to understand the structure of services provided for students with intellectual developmental disability in your PK-12 schools (public, charter, private). For example, are there already transition programs in place? Are there local non-profits in town that provide services? Many school districts will have work programs designed for students with intellectual developmental disability until they are 21-22 years old. These options are appropriate however; the goal is to provide more options and choices for this population. It is also important to identify if your community wants or needs college as an option for young adults with intellectual developmental disability. You can ask these questions by planning and hosting small town hall meetings at your university and/or conducting a community needs assessment. Most likely you will find your community wants this option and it will be most beneficial to document this community need. The more data you have supporting the start of your program the better. Utilizing consortium groups is one way to collect this information. In many states, statewide post-secondary consortium groups have been created to plan and discuss creating more inclusive PSE programs. When planning these meetings think about inviting politicians, university administrators, campus department leaders, representatives from local state agencies (e.g., regional centers, vocational rehabilitation), school district personnel, teachers, parents of students with intellectual developmental disability, individuals with intellectual developmental disability, advocates, leaders of local/state non-profits, and other community leaders. The more people that you have attend the better. Be systematic and structured with an agenda for each meeting. Always identify the function of the meeting. What do you plan to share? What do you plan to gather? Finally, include a sign-in sheet to record attendance, role of the person attending, and contact information. This will provide you with evidence of interest, topics addressed, and can be used to identify those who may have interest in serving on an advisory board, networking services, or contributing/participating in the program.

It is also important to examine the basic types of programs in reference to the best fit for your university and community culture. During the first consortium meeting, you could present the three main types of PSE models found in Hart et al. (2006). You may also utilize any of the program exemplars found through Think College. Although the authors of this guide strive for an inclusive individual support model as the gold standard, other teams may advocate more for a mixed/hybrid model. The type of model you choose should reflect the needs identified in your community and the mission of your university. In addition, you will want to discuss with the local school districts the possibility of dual enrollment. In your review of programs, you should

identify programs within all three models (i.e., mixed/hybrid, substantially separate, or inclusive individual support) and also dual enrollment programs. You can find excellent examples of the different models as well as effective dual enrollment partnerships. In the experience of the authors, a least restrictive inclusive individual support model will take more time to plan; however, it addresses a more progressive model that is aligned with a typical college experience. As you begin your program, it is possible to begin with a hybrid/mixed model and work towards a fully inclusive support model utilizing a 5-year plan.

Task 3: Set Up An Advisory Board

Throughout the process described above, you will find likeminded people who either are motivated to begin a PSE program or will have a stake in the program in a leadership or participatory role. Invite these people to attend a meeting to learn more about this initiative. Listen to their expressed needs and interests. Offer them ways to be involved throughout the development of the program. As you progress, you will want to create a project board or advisory committee. It is important to define the role and function of the advisory board prior to convening, so do not create this committee too soon. You may want to have several (2-3) town hall meetings before finally asking people to serve on the board or advisory committee. You will need to decide if the committee will function more as a Board of Directors or as a typical Advisory Board that reviews plans, policies, and makes suggestions but does not govern or make decisions. When asking for participation, you should clearly define the roles of members in terms of time commitment and the purpose of the board. You should also explain the program's role in working with the board (e.g., information dissemination, invitation to events). You should review these roles during the first meeting of the advisory board. Committees should be established for identified needs. Some of the roles for advisory committees may be as fundraising leader, community liaison, a disability college advocate, treasurer, etc. As you form your board and committees, keep size and function in mind. Some committees with fewer members may be more directed and are better suited to accomplish a task quickly while larger committees may be more adept at securing diverse viewpoints and information.

Task 4: Meet with Groups on Campus

Establishing a presence on campus may arguably be the most important step in building a program that is embedded within the university system. There are many different organizations on campus that you should meet with. Figure 2 provides a checklist of suggested campus organizations to meet with as you begin planning a program. While Figure 2 is an extensive list, you may identify other organizations specific to your campus that may be important to meet with in developing your program. Meeting with specific groups on campus is important because it will alert them to the upcoming program, work out challenges in systemic policies or procedures, and allow you to be responsive to any concerns they may have. The more people and/or organizations you enlist in the development of your program the better.

The Office of Admissions may be the most natural organization on campus to meet with first. When beginning the process of starting a program, you must think about enrollment or admission into the school. While some PSE programs have created an alternative route to the traditional admissions process, these separate systems may lead to difficulties in student use of university

Department	Purpose	Check
Admissions	Presence on campus	
	 Adjustments to general admission form 	
Registration	 Presence on campus 	
	 Ensure typical registration process 	
	 Ensure participation in new student registration 	
	activities	
Bursar's Office	 Presence on campus 	
	 Establishing program fee and payment options 	
Student Organizations	 Presence on campus 	
	 Gather club or activity information for UL Life 	
	students	
	 Solicit information regarding possible 	
	volunteer/mentoring opportunities	
UL Student Life	Presence on campus	
	 Disability awareness activities 	
UL Legal	 Presence on campus 	
	 Discussion of behavior code 	
UL Police Department	 Presence on campus 	
	 Disability awareness training 	
	 Developing emergency plan 	
Office of Disability	 Ensuring accommodations for students in program 	
Services		
Medical/First Aid	 Provide informational profiles about students with 	
A1 . A	medical concerns	
Alumni Association	 Showcase upcoming program 	Ш
President/Provost Office	Presence on campus	
Tresident/Trovest entire	-	
	Initial program support	
Deans/Department Chairs	Showcase program at Dean's Meeting (provide)	П
· · · · · · · · · · · · · · · · · · ·	successful examples from around the US)	_
Academic Success Center	Presence on campus	
	Plan for academic counseling	
First & Second Year	Presence on campus	
Seminar Program	• Establish volunteer/mentoring/service learning	
Coordinators	opportunities	
	11	

Figure 2. Campus meetings checklist

supports and services. Meeting with admissions and collaboratively developing the initial application process is the most logical. Applications can be modified to denote students as PSE students. This also promotes inclusion when the students are filling out the same application for typical admission. Along with Admissions, meeting with the Registrar's Office is also most naturally one of the first stops. You will want to ensure the students are able to go through the regular registration process. This regular process can be supported through a PSE advisor. This PSE advisor should meet with students to help organize initial registration and coordinate various registration activities. As part of the orientation and registration process, many schools have mandatory activities such as club/activity fairs or campus tours where students become familiar with the student ID process, resources, extracurricular events, clubs and activities on campus. By working with the registrar, you can create entrée into all of those activities that make up so much of university life. Some universities have specific advising centers develop and manage these activities. It is important to identify what office on campus is responsible for developing these activities to help promote an inclusive environment.

While planning your program you must decide on a program fee. This program fee is in addition to any registration fees. The purpose of this program fee is primarily to hire the appropriate staff to provide the necessary supports for your program. Depending on the funding support you receive, additional funds will be required to pay for additional staff to ensure quality and efficiency within your program. The Registrar can set up all payments through the Bursar's Office. As decisions are made regarding fees, the Bursar's Office should be informed.

Student government leaders are important to meet with as well. At these meetings, it is helpful to request the opportunity to present the program to the various student organizations on campus. This will give you knowledge of potential groups your students can take part in but also inform various groups on campus of your program and volunteer/mentorship opportunities within your program. Meeting with student government leaders also may give them an opportunity to plan activities around disability awareness.

A meeting with the university legal team (i.e., general counsel) is also important. The legal team can assist in identifying potential issues and creating solutions for those issues. There are many on campus who may be completely unaware of PSE programs and have limited experience with students with intellectual developmental disability. It is important that the legal team is aware of your presence on campus. Reassuring this group that students in your program will follow the same undergraduate guidelines and handbook that every other undergraduate student is expected to follow, while addressing any concerns they may have, is critical to a successful launch. The legal team's job is to anticipate issues. Work with them in problem solving through those identified concerns in order to lay a strong foundation on campus for your PSE program.

Much like the university legal team, the university police department should also be a collaborative part of your initial development. Making the police department aware of your program's presence on campus is critical. Additionally, providing the reassurance that PSE students follow the same university behavior code as every other student will be important to secure police department support. When meeting with them you should offer disability awareness training within their department. As often as possible with all organizations, reciprocal offers should be made to provide training that increases awareness of disability or to

participate in activities that will be inclusive of your students. Building this relationship with university police will also give you an opportunity to develop an emergency plan in case a student gets lost, needs assistance, etc. If there is a medical/first aid group on campus, you should provide profiles of your students. Many times, the medical/first aid group on campus may be associated with the university police department as they are most likely the first responders on campus. Similarly to the university legal team, the university police department may be able to identify potential issues and be able to work through many of those issues.

Another critical group on campus is the Office of Disability Services (ODS). Some PSE programs are managed through this office but collaborate and develop strong partnerships. Partnering with this group will allow you to ensure that ODS provides the same accommodations to PSE program students as they do for typically enrolled students with a disability. There is precedent for this in the AHEAD white paper (Thompson, at al., 2011) recommended earlier. You will want to work with this office to deliver accommodations in typical classes as much as possible. Additionally, if there is a separate lab or testing services for students with disabilities, you will want access to those for your PSE students as well.

Building this program without the support of your dean is futile. As you develop this program, keeping your dean abreast of the planning stages, inviting his/her participation in advisory board meetings, and listening to any concerns voiced regarding the program's presence on campus will be critical for your future support. The department chairs in your college are also essential. As you develop the program, it is strongly recommended that you attend a university dean's meeting to showcase the program. Your dean's support at this meeting will be critical so be sure he/she is not surprised by anything shared there. You will want to make sure you have the foundational program aspects decided prior to a meeting with deans as they will have many questions and will expect clear answers. If you meet before the basic foundation is clear, you risk one disapproving dean derailing your momentum. It is important to share with them the purpose of this program and facts about successful programs around the U.S. Many at the meeting may have concerns about faculty obligations, students' abilities, and liability. Your dean will be able to help you anticipate these questions. Share support plans for students in typical classes and contact information for your PSE program faculty/staff. Share a research brief with findings from other programs and potential research and/or funding opportunities on your campus. Think College has easily shared fact sheets and insight briefs that can provide quick research based information and knowledge to clearly lay out your program foundation. Other key leadership figures such as the president or provost are also significant in initial support. Once again, having your basic facts identified prior to a meeting with either or both of these people is critical to your continuing success.

Finally, there may be an Academic Success Center (ASC) on campus. If present, it is important to meet with them. You may have PSE students who are academically ready to take all classes for credit. If those students are not previously enrolled as typical students, an ASC can provide academic counseling to guide the student. In this same vein, it is a good idea to contact first and second year seminar program coordinators across your campus. Most universities have first and second year seminar undergraduate requirements that frequently include a service-learning component. Recruiting volunteers through this service-learning component is one way to develop a strong network of peer mentors and program volunteers with same aged peers.

This is an extensive list of suggested meetings. However, it cannot be emphasized enough that establishing a solid network of support on campus is critical for establishing and maintaining a PSE program. The more comprehensive your planning is in the early stages, the easier it is to adjust smaller details after the program is off the ground. Being in tune with the organizations on campus that direct university systems and experiences is most important. There may be people or organizations unique to your campus not included on this list that should be added for your program.

Task 5: Funding

Arguably one of the most important parts of initial start-up of a program is funding. If you do not have money you do not have a program. There are many ways to fund a program, all of which are not easy. Funding can be the biggest deterrent to starting and sustaining a program. It is important to have a strategic funding plan before starting your program. This may mean you need to start with one student (or a few) and build to scale while implementing a fee. It is imperative you have a funding plan and are following it strictly.

Grants can be pursued on the federal, state, and corporate level. Since there are not an abundance of federal grants, it may be more appropriate to look at the state and corporate level to help fund the initial start-up of a program. Grants are competitive and will require you to present a thorough plan that is ready to implement if awarded monies. Your state's Developmental Disabilities Council may have funds to put towards initial development. Foundations and/or corporations like Shell frequently offer competitive grant programs. Various state and local partnerships may also provide funding. Dual-partnerships with the local school district may provide the per pupil expenditure to allow for program staff (e.g., coordinator, educational coach, career specialist, community outreach/fundraising specialist). State partnerships with the Bureau of Vocational Rehabilitation (BVR) may provide funds to cover student tuition costs or program fees. In many states across the U.S., the BVR has determined set amounts specifically for tuition for PSE programs. You should study those models to present to your state BVR if you live in a state that does not provide support for PSE programs on an inclusive college campus. In almost every TPSID PSE, the local BVR has played an important role, not only with tuition resources, but also direct services, consultation, and participation on advisory committees (Grigal & Smith, 2016). Developing a partnership with your local BVR is advantageous. When preparing a letter for support from your local BVR, study Vocational Rehabilitation Partnerships with Higher Education Programs Serving Students with Intellectual Disability (Grigal, & Smith, 2016). Grigal and Smith have prepared a Fast Facts issue that can be used in a supporting letter to potential partners in your local BVR.

Private funding is also a way to support the funding needs of your program. Private funds typically come from donors who contribute substantial amounts of monies to support program staff and materials. With limited private monies, this may also include program fundraising events to cover the remaining program costs.

An important conversation you must have with your university and staff is sustainability after the grant monies are gone. Much like the concept of generalization, your end goal should be to create a program that will be maintainable through naturally occurring systems and supports.

Planning for this from the beginning is critical. You will need to have a plan in place to apply for future grants or be ready to implement a comprehensive program fee applied to each student attending the program. Sometimes, a combination of both may be necessary.

As mentioned in Task 3, you may need to consider a per student program fee if you do not have full funding through grants, state agencies, or private sources. This program fee is on top of university tuition. These fees should be calculated to cover program costs. Program fees are not uncommon when you examine many of the 267 programs across the country; however, charging a fee often prohibits students from lower socioeconomic status.

Task 6: Space

You will need to establish space for the program. With the idea of an inclusive individual support model, you do not need classroom space. You should be able to use the library, the student union, or other typical tutorial spaces for one-on-one work with students. However, you will want an office space. This office space will also function as a basecamp space. Most programs establish a basecamp where students can check in with staff if needed, receive tutorials, etc. For example, many programs across the country fall under the umbrella of University Center for Excellence in Disabilities (UCED). These centers often carve out small space for the program that serves as a basecamp. Space should be easily accessible and preferably, centrally located on campus. Be aware; students should be allowed to navigate campus in the same way typical students do. Supports should be individualized and should not resemble a special education classroom. Consider graduated assistance based on each student's individual needs. For example, during the first two weeks of school a peer-support may be with the PSE student almost 100% of the day. Your goal should be to make this 0% as quickly as possible. Obviously, everyone is different so it will take each student a different amount of time to reach that goal.

Task 7: Specific Details

As you start initial plans for a program, there are several foundational pieces you want to put in place. Correlate your program mission statement with your university's mission statement. In addition, you will want to begin to plan specific internal and external objectives. The external objectives refer to the duties needed for program foundation purposes (e.g., collaborations, payment procedures, admissions) whereas internal objectives are the goals designed for the students (e.g., daily living, academic, employment). Identify the name, application procedures, acceptance procedures, program assessment procedures, cost, scheduling procedures, completion procedures, and completion certificate prior to beginning. You can look at many different programs for comparative data. Return to Task 3 in Part 1 and examine each of the programs suggested there to determine how they operate in these areas. Many programs have shared their admission forms, mentoring procedures, etc. and have been uploaded to the Think College resource site. These are going to be separate forms and you may want to include more documents such as IEP, assessment information, checklists, etc. Choose the pieces that fit best for your university. Modify or create a better support if necessary. These procedures become your plan for your PSE program. Create a consumable way to share this (e.g., a handbook). Develop this plan collaboratively with your Advisory Board. Once all of these pieces are in place, it is time to put your plan to work.

Find a good person-centered program to use as a template and make sure to focus on individual behavior and academic goals. The Florida Consortium on Inclusive Higher Education has a template and module available for anyone to use (http://fcihe.com/resources/fcihe-online-learning-modules/star-person-centered-planning/). Remember, these programs are not one size fits all. Just like for typical students, it is highly unlikely that students' schedules in a PSE program are identical. Utilize person centered planning to individualize programs to meet the needs of each student.

Task 8: Plan for Future Research

When starting a program, conducting research may be the last thing on your mind; however, by triangulating the research into your program design discussions it will not only set you up to have a program based on best practice but it will also help build clout to your university administrators. From the authors' experiences, deans, provosts, and other administrators want to hear about the research that the program will produce. It is not that they do not appreciate the community service aspect but they want to see that faculty members are being parsimonious in their community service, research, and teaching responsibilities.

Part 3: Getting Off the Ground

Task 1: Make an Application Process and Recruit Students

As noted in Part 2 you will need to create a separate application for your program. It is suggested that the application will provide you enough information about the students. You may ask for videos, talents, have a checklist, charge an application fee and only accept those applications that are complete. Some applications may look similar to published adaptive behavior scales. It is important to let the community know that you are not assessing their student, but only looking for a quick snapshot of their academic and functional capabilities.

Once the application process has been completed, an interview process should be created. Ideally you should have clear rubrics for application review and the interview process. This process should be created with the help of and approved by your advisory board. Throughout the application review and interview process, you should consider including an outside reviewer. As you combine clearly defined rubrics and an outside reviewer you create a fair process and eliminate personal bias any team members may have. The outside reviewer may be a member of your advisory board or member of the community.

Task 2: Recruit Mentors

Once you have determined students and the supports they will need, you will need to recruit mentors. There are several ways to set up a mentoring program. You can have mentors who support both academic and social progress. You can have paid or unpaid mentors. You can set up mentoring as a service-learning program or as course credit. You can learn more about mentoring and access modules at https://thinkcollege.net/think-college-learn/educational-coaching-and-mentoring/coaching-and-mentoring-supporting-students.

Task 3: Build Awareness

Remember that elevator speech? It is going to be extremely important once the shell of the program has been created. You will need to build awareness at the department level (to help recruit mentors), at the university level, and in the community. A great way to build awareness is to work closely with first- and second-year seminar programs as previously stated. Many, if not all of these programs, have a service-learning component within the course. At many universities, the seminar courses are undergraduate requirements all freshman and sophomore students are required to take in order to fulfill graduation requirements. This can be a large network where younger college students have the opportunity to volunteer early in their college career. They may share this experience with fellow undergraduate students and it may increase the likelihood they continue to volunteer as they progress in their undergraduate studies.

Task 4: Become a Certified Transition Program

Early on, begin your application to become a Comprehensive Transition Program (CTP). This will allow access to financial aid and will allow the program to be accredited. You will want to make sure you set up your program aligning it to standards provided by Think College which provides many resources, including a webinar (http://www.thinkcollege.net/topics/think-college-standards). Think College also has a module for becoming a CTP (http://www.thinkcollege.net/think-college-learn).

Task 5: Continuous Evaluation

It is important to have a planned evaluation technique in place. Initially, unless utilizing external funding, you may not be able to afford an outside program evaluation; however, you will still need to plan to continuously evaluate the program. During the design phase, you should have created both internal and external objectives for the proposed program. Make sure that these objectives are operationalized and task analyzed if possible so that evidence can be collected to make informed decisions about the progress of the program. Designing and updating a logic model and examining the inputs, outputs, and outcomes could also assist to make formative and summative decisions.

Important Implications for Practice and Policy to Promote Inclusion

There are many learning curves ahead when starting an inclusive PSE program. Everyone's experiences are going to be different because every university/college is different. Based on the authors' experiences a few themes should be considered when creating a PSE program.

Bigger is Not Always Better

You may encounter many difficult decisions around the acceptance process of students. It can be a difficult decision not to increase admissions and even harder to decline students of admission to the program; but bigger is not always better. It truly is important to think about the quality over the quantity of the program that is being created. As with any innovative program it is always better to start small.

Practice What You Preach

In addition to their involvement with PSE programs, the authors are also instructors of courses in intellectual developmental disability. Having an inclusive program on campus can provide opportunities for internships, tutoring, and/or other service related opportunities. This gives professors and instructors opportunities to use the strategies and techniques they teach future teachers in the field each semester. As professors and instructors share first-hand experience, it can lead to increased credibility among students in the course/program.

My Way is Not the Only Way

Be open to other ideas; learn from others. There is no need to recreate the wheel. With the TPSID projects and the creation of the National Coordinating Center, there are already a lot of resources available to access. In addition to the TPSID projects, there are many other programs out there. Do not hesitate to send an email or call others to ask questions. You will actually find that everyone wants to build these opportunities and help others and few pretend to have all the answers (including the authors of this article).

Get the Campus Community Involved

Figure 2 refers to the people that you will or should contact as you begin to plan for your program. Remember, the more the better. From the authors' experiences, you will be surprised the number of people that will step up and help take charge in a number of initiatives. They may get involved because they have a family member with intellectual developmental disability or they realize it is the right thing to do. Either way, it helps to build a community within your campus.

Your Biggest Enemy Can be Your University

It is a bit hypocritical to say this after just stating that it is important to get your campus community involved, but as you explore the previous considerations, you may encounter this roadblock. The heading is not meant to sound negative because every profession has difficulties implementing new ideas; however, it is important to know that the university and/or college systems are not always easy to navigate. There may be high turnover, employees who are unmotivated, employees with the wrong answers, employees that tell you what you want to hear, and (unfortunately) employees that do not agree with what you are trying to accomplish. Avoid confrontation at all costs and, when you hit roadblocks, rethink your plan. Do not get frustrated and do not give up. Remember there are 267 colleges that have done it. You may not be able to design your program identical to the others due to these roadblocks, but there are always going to be compromised alternatives.

Keep it Inclusive

These programs were created in order to provide an inclusive college experience for young adults with intellectual developmental disability. In high school, young adults with intellectual developmental disability see their peers and friends go off to college and they are told that they

are not allowed. That is no longer the case. Make sure you do not go backwards in time. Keep it inclusive. If your program has a separate room, separate classes, separate curriculum then the students might as well stay at their separate schools. It is difficult to design a fully inclusive program; however, the results will be worth the time and effort.

Conclusion

This article has indirectly addressed a number of implications for practice to promote the inclusion of individuals with intellectual developmental disability. To borrow again from Storlie et al. (2016), the past decade has brought numerous cultural trailblazers in the form of nervous young adults with intellectual developmental disability that have taken that step to fulfill their long-time inclusive college dreams. Many lifelong educators of students with disabilities have refocused their careers to help pave the path to postsecondary education. It has not been an easy path; however, as more PSE programs are established, it becomes easier and more typical. The programs across the country not only provide a great opportunity to young adults with intellectual developmental disability but also create a more inclusive community. These programs more closely connect colleges and universities to their missions of lifelong education and education available for everyone. The framework offered here is meant to facilitate attempts to build inclusive programs successfully within your university, community, and state. Utilize this framework as a support tool on the pathway to creating your own inclusive PSE program for students with intellectual developmental disability.

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Physical Disabilities: Education and Related Services, 2018, 37(2), 34-59.

doi: 10.14434/pders.v37i2.26254

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ISSN: 2372-451X

http://scholarworks.iu.edu/journals/index.php/pders/index

Article

TRAINING AND PREPAREDNESS TO MEET THE NEEDS OF STUDENTS WITH A CHRONIC HEALTH CONDITION IN THE SCHOOL SETTING: AN EXAMINATION OF TEACHER PREPARATION PROGRAMMING IN THE UNITED STATES

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Abstract: Despite the increasing prevalence of chronic health conditions among youth in schools, teachers report little exposure to specific coursework focusing on how to best support students with these conditions in the classroom. This study examined how teacher preparation programs prepare educators to meet the needs of this growing student population; findings also include survey results describing level of preparation to support students with a chronic health condition from the perspective of preservice and practicing educators enrolled in the nation's leading colleges of education. Results suggest that dedicated curriculum to prepare teachers to work with students with chronic health conditions is largely absent from teacher preparation programming, and that teachers feel they lack knowledge to adequately support students with a chronic health condition in the classroom setting. Recommendations and implications are discussed.

Keywords: chronic medical conditions; chronic health conditions; teacher preparation; teacher training

Introduction

School support for students with chronic health conditions is a relatively new and thus continuously evolving topic, given that decades ago, considerations for students with health conditions were largely deemed unnecessary due to low survival rates and poor long-term outcomes associated with most serious pediatric conditions (Pufpaff, McIntosh, Thomas, Elam, & Irwin, 2015). In a span of 34 years, however, several factors have shifted the dynamics associated with school for students with chronic illness. Perhaps most notably, the population of students shifted from what was previously deemed a low incidence to now a high incidence population, as cure rates for most pediatric illnesses have increased significantly (Aruda, Kelly, & Newinsky, 2011). Furthermore, for those with the most severe (and even incurable) conditions, advances in technology have allowed for children who historically would have been institutionalized to be treated on an outpatient basis, thereby increasing their participation in the traditional school setting (Perrin, Guyer, & Lawrence, 1992).

Despite the increased prevalence of students with a chronic health condition (or history of), the education field has been slow to catch up with the ever-growing demands of this student population (Pufpaff et al., 2015). Given the known implications associated with chronic illness (including compromised academic, social, emotional, and behavioral outcomes), it is widely understood that these learners warrant unique and specialized supports in the school setting, though research is limited in evidencing best practice and interventions most effective for students with a history of chronic illness (Roberts, 2006). Thus, it is no surprise that educators report worry, fear, and lack of preparedness relative to supporting this population of youth in the classroom (Heller, Fredrick, Best, Dykes, & Cohen, 2000; McCarthy, Williams, & Eidahl, 1996). Further contributing to teacher reluctance and confidence in supporting students with health conditions is the absence of teacher preparation and professional development on this topic (Bradford, Heald, & Petrie, 1994; Pufpaff et al., 2015). In 2004, it was reported that 59% of teacher respondents endorsed that they had not received any academic preparation and 64% had not received on-the-job training for supporting students with a chronic illness, yet nearly all (98.7%) reported knowing a student with such a condition (Clay, Cortina, Harper, Cocco, & Drotar, 2004). Six years later, the National Association of Secondary School Principals published the following statement:

The gap between professional preparation and the need for knowledgeable professionals with regard to medical issues is wide. Without changes in preservice and in-service preparation, this gap is likely to grow wider (Shaw, Glaser, Stern, Sferdenschi, & McCabe, 2010, p. 16).

Most recently, Selekman (2017) illuminated that this issue persists, reporting that 52.3% of more than twelve hundred teacher survey participants described they received no training on children with chronic conditions as part of their teacher preparation programming; an additional 16.9% had only one lecture on the topic, and just 8% indicated that their preparation was helpful for this aspect of their role.

Failure to address this aspect of teacher training is not without consequences. Research on teacher perceptions suggests that there are many misperceptions about this population of students,

and these misunderstandings often translate into misguided focus and stereotypical attitudes which can compromise supports that would otherwise benefit these learners. For example, Olson, Seidler, Goodman, Gaelic, and Nordgren (2004) identified that educators may perceive that students with health conditions pose a threat in terms of personal liability and risk in the classroom for the educator, when, in reality, students with chronic illness are more likely to experience psychosocial difficulties and challenges with learning. The likelihood of these students having a medical emergency in the classroom and therefore creating liability risks for the teacher is very low. Though evidence exists to the contrary, and as Olson and colleagues reinforce, "few educators perceived their students' [with chronic illnesses] learning abilities as an issue" (Olson et al., 2004, p. 56). This unfortunate misunderstanding can result in educators overlooking indicators that may reveal a need for traditional classroom supports for their students with health conditions.

Completing a training program specific to increasing knowledge of chronic health conditions and associated treatments has been shown to significantly increase knowledge levels from pretraining to post-training among educators (Brown, Bolen, Brinkman, Carreira, & Cole, 2011). Prevatt, Heefer and Lowe (2000) endorsed the value of training, reporting that appropriate school personnel education programs may prepare educators to meet the overall needs of students with chronic health conditions by providing information and training that aims to increase the understanding and sensitivity necessary to successfully meet such student needs in the classroom. Cunningham and Wodrich (2006) further substantiated the positive effect of teacher preparation in this area; their study demonstrated that when teachers are provided with basic disease information and the associated classroom implications, the amount and type of accommodations designated more closely aligned with the specific needs of the student compared to teachers that did not receive such targeted information.

To date, while the literature suggests that teachers are ill-prepared to support students with chronic health conditions in the classroom, a thorough review of the availability of such curriculum and training is seemingly not available. Therefore, the purpose of this research was to determine how teacher preparation programs prepare educators to support the school-related needs of students with a chronic health condition and, secondarily, to examine the perception of need and level of preparation in this area from the perspective of preservice and practicing educators enrolled in colleges of education nationwide. Specifically, this mixed-methods study examined three research questions:

- 1. How do national teacher preparation programs prepare educators to support the school-related needs of students with chronic health conditions?
- 2. Are there any teacher preparation programs in the United States that seek to train educators on the school-related needs of students with a chronic health condition?
- 3. What is the perception of need and level of preparation relative to supporting students with a chronic health condition in the school setting from the perspective of the preservice and practicing educators enrolled in colleges of education across the country?

Methods

A combination of structured interviews, surveys, curriculum reviews, and a comprehensive web search were employed to answer these research questions. Table 1 outlines the research question and provides information on the research methods, related instrumentation used to address each research question, and the source for information or the sample for each research question.

Curriculum Review

To assess how teacher preparation programs across the country prepare educators to support the school-related needs of students with a chronic health condition (research question 1), the research team designed a Curriculum Evaluation Tool, a list of inclusionary/exclusionary terms, and steps for website review. The following steps were used to evaluate webpages: identify the official college webpage; search within the webpage for college of education (undergraduate or graduate); locate degrees offered within the college; locate course catalog; locate degree requirements; and then transfer data into the Curriculum Evaluation Tool. Three members of the research team examined the curriculum of 40 teacher preparation programs across the country to determine how these programs prepare educators to support the school-related needs of students with a chronic health condition.

A team of expert reviewers determined required courses for each major, minor, or certificate. While searching for any indication that curriculum in these programs specifically teaches the preservice and practicing educators how to support children with chronic illnesses in the school setting, researchers also searched for content related to other unique populations of students to compare whether other unique populations of students were explicitly cited in descriptions of teacher preparation courses as an area of focus (e.g. students with autism, English Language Learners [ELL], gifted students).

Structured Interviews

To supplement the findings from the curriculum review phase of this study, the curriculum review was followed by an attempt to interview the National Council for the Accreditation of Teacher Education (NCATE) Coordinator, curriculum director, or other faculty member responsible for curriculum development from each of the 40 identified teacher preparation programs. Potential participants were identified using the university's/program's website and/or by calling the program directly. A study recruitment script was used via phone and/or email to invite the curriculum representatives to participate in the research. Three attempts were made to invite each curriculum representative, and if the first university staff member (e.g., NCATE Coordinator) identified was not successfully recruited, study participation by another staff member at that university in charge of teacher preparation curriculum development was sought (e.g., Special Education Department Chairperson, a curriculum director, a department chairperson, the college dean).

Table 1

Research Questions, Methods of Data Collection, Source of Information, and Instrumentation

Research Question	Method	Source/Sample	Instrumentation
1. How do too show	Curriculum review	Curriculum guides/course descriptions of 40 national teacher preparation programs (20 graduate & 20 undergraduate)	Curriculum examination data collection tool
1. How do teacher preparation programs nationwide prepare educators to support the school-related needs of students with chronic medical conditions?	Structured interviews	Curriculum representatives (NCATE Coordinator, curriculum director, or other faculty member responsible for curriculum development) from undergraduate and graduate teacher preparation programs nationwide	Curriculum interview protocol
2. Are there any teacher preparation programs in the United States that seek to train educators on the school-related needs of students with a chronic health condition?	Web Search	Extensive web-search using a defined set of search terms to identify teacher preparation programs in the United States that seek to train educators on the school-related needs of students with a chronic health condition	Web-search data collection tool
3. What is the perception of need and level of preparation relative to supporting students with a chronic health condition in the school setting from the perspective of the preservice and practicing educators enrolled in colleges of education across the country?	Survey	29 students in one of the previously identified 40 teacher preparation programs	Investigator- designed perceptions survey

The interviewer received consent from participants and interviews were audio recorded. Early in the interview process with each interview participant, the researcher transparently reviewed the results of the associated curriculum review to give the university's curriculum representative an opportunity to speak to the findings of the curriculum examination for his/her program. Memberchecking concluded each interview and interviews were transcribed and cross-transcribed.

Web Search

To determine if any teacher preparation programs in the United States seek to train educators on the school-related needs of students with a chronic health condition (research question 2), an extensive web-search (using a web-search data collection tool developed by the research team) was conducted using the Google search engine to identify teacher preparation programs in the United States that claim to train educators on the school-related needs of students with a chronic health condition. Search terms included various combinations of the following terms: [teacher preparation, teacher training, teacher credential, teacher certificate] coupled with [chronic illness, other health impairment, health disability, special health care needs, mental illness, chronic illness and orthopedic impairment].

Survey

To respond to the third research question on the perception of need and level of preparation relative to supporting students with a chronic health condition in the school setting from the perspective of preservice and practicing educators enrolled in colleges of education across the country, a small sample of preservice and practicing educators enrolled in the previously identified teacher preparation programs (from programs that also participated in the interview portion of the study) participated in a survey to examine perceptions of training. University instructors and professors who expressed a willingness to allow the students in their teacher preparation courses to participate in this survey were sent an email template with a recruitment script and a link to the electronic survey. University personnel who shared the survey with the students in their teacher preparation classes received two tools in PDF form via email (a chronic medical conditions accommodation recommendations tool and a chronic medical condition plan of care form) designed to support students with chronic health conditions in the educational setting as an incentive and were encouraged to share these tools with students in their courses. The final sample included 29 students, each of whom were current students taking at least one course in the respective teacher preparation program being evaluated.

Data Analysis

Curriculum Review

A separate Curriculum Evaluation tool was completed for each of the 40 schools. Three researchers read each course title and description and cross-referenced the content populated for each school and the assessment of content completed by the previous researchers. In instances in which the research team did not agree on a portion of the assessment, the team re-evaluated as a group and reached consensus. If the team had questions about the curriculum for any particular

course, the team made note of the question to be included in the follow up interview with the representative of that program.

Structured Interviews

The interview data were also examined at the question/item level by three members of the research team using the inductive analyses approach described by Thomas (2003): close reading of data (read and then reread) was conducted; a coding template was used to organize the analysis; themes were identified and a consensus on themes was achieved.

Web Search

Three investigators used the previously described web search tool to conduct the search and analyze findings. Results related to teacher training programs (affiliated with a university, college, or other formal training program) were included in the final product and the researchers eliminated results that were not affiliated with teacher training, such as courses tied to medical schools, training for medical professionals, and university-level training to teach or support individuals with a chronic illness.

Survey

Frequencies were calculated to assess demographic and participant characteristics, level of knowledge for taking care of the medical and educational needs of children in the classroom by different chronic health conditions (e.g., asthma, diabetes, cancer), level of training offered by the program regarding taking care of the medical and educational needs of children in the classroom by different chronic health conditions, and current methods offered by the program (e.g., single course, this topic is embedded throughout the curriculum) to prepare teachers to work with their future students who have a chronic health condition. A chi-square analysis was performed based on grade level to identify whether students enrolled in colleges of education that offered academic opportunities to prepare them to work with students who may have a chronic health condition differed between undergraduate and graduate-level programs. To determine the association between grade level and level of awareness of educational issues experienced by students with a chronic health condition, a one-way analysis of variance (ANOVA) was performed. This analysis was replicated to examine the association between educational specialty track and level of awareness of educational issues experienced by students with a chronic health condition.

Results

Curriculum Review

Table 2 summarizes the results of the curriculum analysis, coupled with prevalence estimates of each of the unique student populations that are typically addressed in teacher preparation programs. Results revealed that while the prevalence of students with a chronic health condition in U.S. public schools is the highest when compared to the other student populations (e.g., autism), content about this population had the lowest representation in teacher preparation

coursework. Very few of the 46 courses identified as addressing chronic illness actually addressed content specific to chronicity, illness, chronic medical condition, sickness, special healthcare needs, health condition, or medical impairments. Rather, most of the 46 courses were included because they mentioned the Other Health Impairment special education eligibility criteria (per IDEA) in the context of the course description.

Table 2

Curriculum Review Findings

Category	No. Courses	No. Courses Undergraduate Vs.	
	Identified	Graduate	Prevalence
Autism	112	U - 65	1 in 59 children ¹
		G - 47	
Chronic Illness	46	U - 39	1 in 4 children ³
		G - 7	
Mental Illness	74	U - 53	1 in 5 children ²
		G - 21	
English Language	524	U - 345	1 in 10 children ⁴
Learners		G - 179	
Gifted/Talented	177	U - 129	1 in 7 public school
Learners		G - 48	children ⁵

Note: U = undergraduate programs, G = graduate programs; *Citations indicated on reference list.

Structured Interviews

Fifteen university representatives (11 undergraduate and four graduate) participated in the interview portion of the study. At the start of each interview, results of the Curriculum Review were reviewed with each interview participant. While some participants provided explanation and clarification, all 15 university representatives agreed with the results of the Curriculum Review for their respective school. Table 3 presents the 12 themes within five categories that emerged in the analysis of the interview data.

Defining the population. Within the first category, *Defining the Population*, two themes were identified. The first common theme, Who Are They?, captured program representatives' responses that demonstrated a lack of understanding of who is included in this unique student population. Several participants correctly alluded to a few diagnoses that may be included within the category of a chronic condition (e.g., attention deficit hyperactivity disorder [ADHD], asthma, and diabetes), although most did not. A majority of the interviewees considered students with a chronic health condition as a low-incidence population and identified the population as encompassing exclusively students who are medically fragile. Statements associated with this theme, and represented by several examples in Table 3, indicated that participants believe students with a chronic health condition are likely too ill to attend school, asserting that as a result, not much attention is given to this population in preservice training, assuming if these students were in school, they would not be in a typical

Table 3
University Representatives Interview Results

Category	Theme	Explanation	Example Participant Quotes
Defining the Population	Who Are They?	Used when participants misidentified the population, for example: Thought population was only medically fragile students or students who had severe cognitive delay or students who had multiple disabilities or to be included in the low-incidence category	"We're in ***, so if there was a child that had a chronic illness where they needed an extended hospital stay, they would not stay here. They would go to ***, which is five hours away." "Some of the barriers are actually getting all that equipment into the classroom. Um, you know the uh, the bed that the child might be in, or um the tube feeding, or the um IVs or whatever the case may be."
	Special Education	Used when participants identified Special Education as the area that would or should cover teaching preservice teachers about the educational needs of students with chronic health conditions	"most of that would come through our special education uh, department. And uh, as far as a core class, where they get information in dealing with special needs populations and that is included, medical is included in that particular course." "I don't know how much we do with chronic diseases; I would have to find out from my special ed person because that would be the likely location for that" "our low-incidence they're very involved in feeding aspects also. That's what we considered to be one of the key members of the team, is the nutritionalist, or the speech language pathologist, or an OT that's working with the students with feeding issues."

	They are Doing It	Used when participants endorsed some type of dedicated effort in their curriculum relative to preparing teachers to support students with chronic health conditions (e.g., if they include coverage of the topic in a special education course)	"I believe there's a chapter or there may be a section, I'm pretty sure there's a section in there that deals with chronic illnesses. Probably especially as those impact or cross over into the area of disabilities, so like for example traumatic brain injury, or maybe other health impaired or other impaired." "it's embedded within a course, but is not the main focus of a course" "a course in child health, safety and nutrition [], that specifically helps students understand, preservice teacher[s], understand chronic conditions and how to adapt them for the classroom."
Teacher Preparation for Students with CHC	They are NOT Doing It	Used when participants indicated that they do not provide intentional instruction relative to preparing teachers to support students with chronic health conditions	"I don't think specifically to children that are, that have a chronic illness, but um, children with disabilities. Um, and how to assist those." "know that diabetes, things like that, can be chronic, can be considered chronic illness. Asthma, that kind of thing. But that doesn't impact their learning, [so] that's not something we deal with in the classroom necessarily." "cancer and those things, we really don't touch on a lot of that. Not on purpose, necessarily. Um, I do you know, discuss a lot about autism, ADD, ADHD"

Barriers to Providing Dedicated Instruction	Barriers-Time	Used when participants described lacking time as a barrier to including intentional instruction/content	"We are so constricted by our state and the number of hours that we are allowed to put on degree plans. We have 139 hours, and they made us get down to 124. And we have a waiver because they want all degrees to be 120 hours. So I can't, I mean I don't see that happening, because we just don't have room on our degree plans. And if we have electives, they're not going to take it." "[time]the main barrier, because, [] our state certification is so broad and [] we really want you to experience a lot of these different things, but we can't, you know." "we can't possibilityteach our students that every single possible um, health and physical issue, every disability."
	Barriers- Curriculum	Used when participants described curriculum demands/limitations as a barrier to including intentional instruction/ content	"We've got so many different things to cover in the statute, um as they're as they're currently written. And only and, because we're under increasing pressure to get kids out at 120 credits." "I think there might be barriers are far as um, how many we in our special education program get [meaning courses or credits] to influence the teacher ed students." "We've really paired down as much as we can [] to remain competitive with all the other external certifiers in the state."
	Barriers- Lacking an Expert	Used when participants described not having someone who is an expert in this area as a	"I don't have theexpertise to be able to gear like an entire section of the course or section of material towards [CHC]"

		reason why they would not be able to provide more education for preservice and in-service teachers in this area	"We could probably use a faculty member with more expertise in that area, um but we just don't have the resources at this point."
	Applying a General Framework	Used when participants endorsed the application of a general framework as a preparation strategy to prepare teachers to work with students with CHC	"we don't have a specific course related to students with medical conditionswe would handle it more under a particular disability area, or a particular label" " [our] approach is a much broader brushwe have an entire course on teaching the diverse learnerthe central core of it is essentially saying how do you look at each child as an individual and get to know them from what their specific set of needs and interests and readiness" "I think they [preservice teachers] have a very global awareness of how that [CHC] might impact the child's learning, integration, socialization, and academic performance, and all that. But the specifics, from my experience, usually come onsite at that school, during the preservice and the induction process."
Solutions & Problem-Solving	Workaround	Used when participants described an existing strategy or a strategy they would be interested in employing in an effort to prepare preservice teachers to work with students with CHC	"we've had people student teach in classrooms where there are medically fragile childrenwe have like 30 students a semester, so it's not possible for all of them to rotate through that." "every semester, there will be one or two [students who student teach in a classroom that has children who are medically fragile] "within our seminar series,

which is an hour a week, we have brought in [...] a school nurse to talk about health care plans and the role of teachers in those health care plans" "someone from the healthcare field, and have them come in and [...] do either a take a part of a class, or do separate workshops for our teacher education students." "...our special educators [...] take a methods of instruction class for low incidence disabilities and we talk um, quite a bit about specialize, kids with specialized healthcare needs. But, apparently there could be more." "there is an increase in childhood cancer, and some of the allergies, those kinds of things that [...] I think we could better prepare our students to [...] provide services for."

"do talk about different, different disabilities that are served under IDEA, but certainly there's room for more" and that they could be "more systematic about making

sure [their students] know about all [the] different [...] chronic medical conditions that

are possible."

Room for Improvement

Used when participants acknowledged room for improvement compared to current state

	Limited to No Awareness at Graduation	Used when participants described their graduates as having limited to no awareness of how to support students with CHC	"I think they are aware of it, but I think, it's a very limited awareness. Uh, because, when we do our exit surveys, and when we go out and do alumni surveys, um one year out, two years out, and we ask what could we do better. Most individuals say they need more special education classes, learning how to work with uh, children with special needs or medical conditions. So they put, they still put that there. So I, I think, I think they're aware of it, I think they are certainly aware of it, but they still want more." "Most of them will have some textbook knowledge that those kids exist, but that'll be it." "I think they're fairly unprepared."
Supporting New Teachers	Open to It – Content Needed	Used when participants expressed an openness or an active consideration for including content for CHC now or in the future	"Yes, actually we are in curriculum revision right now due to some accreditation. And so we are looking at that, and looking at additional special ed courses and additional courses that deal with um populations, such as uh, medical." "I would say no officially, but after this discussion, I'll probably have it more in my mind, and when we have our program, our cord-our program meeting for our depart, for our department, I'll, I'll definitely be thinking about it even more." "If, if we could figure out a training type of thing that we might could do a PD for our preservice."

classroom setting. As one program representative shared "the high-incidence teachers, [...] get more content in, [...] academic instruction, and less in the medical and personal needs of students cause they're really targeting to be teachers for students with learning disabilities and ...behavior disorders."

The second theme in this category, Special Education, emerged in responses to the question inquiring about types of training experiences offered to preservice and practicing teachers at the respective colleges/universities relative to educating and assisting students with chronic health conditions in the classroom. Ten out of 15 program representatives indicated that this type of training would be covered under the umbrella of special education programing. When asked if these were required classes, almost 50% of the participants (seven of 15) indicated the courses they referenced were required for special education majors, and only three participants stated that general education majors were required to take at least one related course (e.g., Children with Exceptionalities). Most interviewees stated that the information regarding students with chronic health conditions would be covered under the umbrella of special education, but not a main focus of their preparation. Comments also mentioned preparing the preservice special education students in the development of Individualized Education Programs (IEPs) and 504s, with multiple suggestions from participants that this may be a way to address this topic. One program specifically stated they had a unit on health conditions that the elementary and middle school preservice teacher education students were required to take, but that it was an elective for those preparing to be high school teachers.

Teacher preparation for students with chronic health conditions. The following two themes support the second category, *Teacher Preparation for Students with Chronic Health Conditions*. The first theme, They are Doing It, includes active endorsements from the participants suggesting some type of dedicated effort in their curriculum exists relative to preparing teachers to support students with chronic health conditions. Of the 15 college/university representatives interviewed, only one representative shared that there was an entire class dedicated to providing preservice and practicing educators instruction on how to meet the needs of a student with a chronic health condition in the classroom. The participant shared that this class is required for some majors and is an elective for others, but did not say specifically which majors fell under which of the two categories. Any other positive endorsement of covering the subject was largely represented as a possible topic included in a special education course.

Data coded in the second theme, They are Not Doing It, in the Teacher Preparation category included participant responses which indicated that the associated teacher preparation program did not intentionally provide instruction relative to preparing teachers to support students with chronic health conditions (see Table 3). Seven of the 15 participants stated that their respective programs did not currently have dedicated material or courses focused on instructing preservice teachers about the specific needs of this unique population. Three other representatives shared that the most likely place one of their students would receive instruction and/or experience concerning students with chronic conditions is if it occurred in one of their field placement settings, as it is not currently embedded within their programming. Another respondent explained that the lack of instruction on students with cancer was not necessarily on purpose, but that much of their focus was on autism, attention-deficit disorder, and ADHD.

Barriers to providing dedicated instruction. Three types of barriers emerged as themes within the third category, Barriers to Providing Dedicated Instruction (see Table 3). First, six of the 15 respondents identified thematically Time as a barrier for including instructional materials in courses. Four of the interviewees specifically stated the increasing pressure to have students graduate in 120 credit hours as a limitation of what could be added to their already packed degree plans. Similarly, another participant explained "...there's so many disabilities and [their state] has what they call a general curriculum licensure. So we're preparing teachers to work with so many different types of special needs...we get spread pretty thin." Although they could not always include the content and some felt that they did not have expertise on the myriad of illnesses, they saw this content as valuable. As a second theme in this category, eight of the 15 respondents identified Curriculum Demands/Limitations as a barrier for inclusion of this type of dedicated content. As is evidenced by the quotes in Table 3, teacher preparation programs clearly have to contend with curriculum pressures that make it challenging to consider adding content to cover teacher training relative to supporting students with health conditions. Third, Lacking Expertise was another theme related to barriers associated with providing dedicated curriculum. Two undergraduate and one graduate university program identified not having someone who is an expert in this area as a reason why they would not be able to provide more education for preservice and in-service teachers. They acknowledged that it would help to have someone on the staff with more experience and expertise.

Solutions and problem-solving. Related to the fourth category, *Solutions and Problem-Solving*, three themes emerged in the analysis. The first theme, Application of a General Framework, included references to the application of a general framework as a preparation strategy to prepare teachers to work with students with chronic health conditions. In fact, 14 out of the 15 schools that participated in the interview portion of the study endorsed the application of a general framework as a solution to teacher training on this topic. Commonly, the participants representing these 14 teacher preparation programs described perceived issues for students with chronic health conditions as coming up in discussion regarding IEPs and 504 plans and, that by virtue of instructing preservice teachers in how to apply commonly referenced accommodations and modifications for students with special needs, they indirectly prepared preservice teachers to accommodate the unique needs of students with chronic conditions. A few participants described their generalist approach with confidence, asserting that a broad approach is the only way to address the many unique needs of students; yet, one of these participants stated that chronic conditions are not specifically mentioned within their broad approach.

Additionally, several participants mentioned that, within the generalist approach, they teach preservice teachers to rely on others if called upon to meet the needs of a student with a chronic condition. For example, one participant described their strategy as teaching preservice teachers to rely on a team approach, "we talk about the health care professionals, nutritionist, OT's, speech path, social workers, so, you know one response [to how they teach preservice teachers to work with students with chronic conditions] would be making sure to come address student's needs as a team. A lot of our preparation is really based in looking at functions of behavior, and for students to have the skillset to do functional behavioral analysis."

The second theme in this category, Workaround, was a descriptor for comments by participants describing strategies for a quick fix or an easy way to prepare preservice teachers to work with

students with chronic conditions. When asked how participants thought their students should be informed about supporting students with chronic conditions, none of the program representatives specified that dedicated curriculum was necessary, but instead suggested a variety of ways this topic could be incorporated within the present curriculum. For example, one interviewee stated, "I think it would be cool if there were some online modules or something that we could incorporate so that our teachers were better prepared." Similarly, another representative felt requiring preservice teachers to take an online module prior to entry into the program could be a possibility. Offering preservice teachers an opportunity for professional development relative to students with chronic illness was also suggested, as well as partnering with professionals in the healthcare field to volunteer to be guest speakers in teacher preparation classes. Five of the 15 participants mentioned field placement as a possibility for exposure to students with chronic conditions. In most cases, participants acknowledged the limitations of such experiences, and offered that it is likely that only a portion of their students would be able to work with students with health conditions in this way. One participant shared that their "special ed. faculty [...] provide[s] wonderful supports for our students" suggesting that special education faculty could provide guidance to individual preservice teachers on the topic should they have a question and another mentioned that schools should provide this training for teachers.

As participants progressed through the interview, some began to recognize that there may be more that they could do to prepare their students to meet the needs of children experiencing chronicity. Thus, the third theme, Room for Improvement, emerged. For example, one program representative shared that although an attempt is made to provide students with all of the instruction they need to be successful teachers, most of their graduates provide feedback saying "they need more special education classes, learning how to work with [...] children with special needs or medical conditions."

Supporting new teachers. The fifth and final category that materialized in the interview data was *Supporting New Teachers*. The first theme within this category, Limited to No Awareness at Graduation, was used when participants described their graduates as having limited to no awareness of how to support students with chronic health conditions. Ten of the 15 participants shared that their preservice teachers, upon graduation, are likely unprepared to work with students with health conditions. Words used to describe the level of awareness of their graduates included "surface knowledge," "limited awareness," "very limited," and "fairly unprepared."

The second theme, Open to It/Content Needed, captured comments reflecting ideas for including content for school support for students with chronic conditions in the curriculum. Of the 15 colleges/universities interviewed, three representatives indicated that their programs may be interested in adding instruction relative to this topic at the time of the study, and four additional representatives shared that they would be open to the possibility of including this type of instruction into their curriculum in the future. Two of the three participants who felt that their respective programs would consider including this instruction into their curriculum sooner rather than later were in the process of curriculum revisions at the time of the study. One of the four interviewees who stated that they could see their program including this type of instruction in the future referenced the increase in childhood cancer and some allergies as a reason for including this topic in programing. Another representative shared that the current interview was a catalyst for increasing their awareness about the topic. Specifically, the participant stated, "talking to you

has just made me want to [...] try to make a better connection between our program and the [...] physician's assistant program here on campus." All seven representatives indicated this type of instruction would fall within the special education programming and not general education.

Web Search

The combination of search terms "teacher preparation" and "chronic illness" and "teacher training" and "chronic illness" did not yield information about universities/colleges that provided training in the area of children with chronic illnesses. However, the terms "teacher training" and "health disability/health impairment" and "teacher preparation" and "health disability/health impairment" were more likely to yield information about university settings that offered teacher training in working with young children with health impairments (n = 59). Fifty-five of these programs offered a certificate or advanced degree in special education. Nineteen of the programs (29%) described working with children with health impairments as a major program focus. A review of curriculum at these programs indicated that only about 18% mentioned chronic illness terms or health impairment in their program description. When reviewing descriptions of courses for the programs that addressed health impairments, 64% mentioned other health impairment, 18% mentioned mental health and chronic illness, and 54% mentioned orthopedic impairment.

Survey

Demographic and participant characteristics. Of the 29 survey participants, 28 (96.6%) participants were female and one (3.4%) was male. The majority (n = 22; 75.9%) were undergraduate students and 24.1% (n = 7) were graduate students. Nine (31%) students reported they were in special education and 20 (69.0%) students were in regular education or other. Twenty-five (86.2%) students were pre-service teachers and four (13.8%) were practicing teachers.

Level of knowledge and training. When presented a list of specific chronic conditions, overall, participants rated their level of knowledge for supporting the medical needs of children in the classroom as low, with the exception of food allergies (58.6% rated their level of knowledge as high; see Table 4: Levels of Knowledge and Training). The majority of participants rated their level of knowledge for taking care of the educational needs of children with chronic conditions as relatively low, except for asthma (52.0% rated their level of knowledge as high), diabetes (50.0%), and food allergies (60.0%). Regarding level of training for medical needs, a significant proportion of participants (over 90%) rated their level of training offered by their program regarding taking care of the medical needs of children in the classroom as low; see Table 4). Similarly, the majority of participants rated their level of training offered by their program regarding taking care of educational needs of children in the classroom as low for all identified conditions.

Level of awareness of educational issues. A one-way ANOVA was used to examine differences in responses for the level of awareness of the educational issues experienced by students with a chronic condition based on grade level and educational specialty track. No statistically significant difference in level of awareness was found based on grade level or educational specialty track (see Table 5). It is noteworthy that mean levels of awareness were

Table 4

Level of Knowledge and Training Frequency and Percentage

	Level of Knowledge for Taking Care of Needs in the Classroom			Level of Training Offered by Program Regarding Taking Care of Needs in the Classroom				
	Medica	al Needs	Educati Needs	onal	Medica		Educati Needs	onal
Chronic Health Condition	Low	High	Low	High	Low	High	Low	High
Asthma	15	14	12	13	25	2	18	9
	(51.7)	(48.3)	(48.0)	(52.0)	(92.6)	(7.4)	(66.7)	(33.3)
Diabetes	19	9	12	12	25	2	19	8
	(67.9)	(32.1)	(50.0)	(50.0)	(92.6)	(7.4)	(70.4)	(29.6)
Cancer	22	4	13	12	24	2	16	9
	(84.6)	(15.4)	(52.0)	(48.0)	(92.3)	(7.7)	(64.0)	(36.0)
Sickle Cell	21	3	14	10	24	2	17	8
Anemia	(87.5)	(12.5)	(58.3)	(41.7)	(92.3)	(7.7)	(68.0)	(32.0)
Hemophilia	22 (95.7)	1 (4.3)	14 (58.3)	10 (41.7)	25 (96.2)	1 (3.8)	17 (68.0)	8 (32.0)
Cystic Fibrosis	20	5	14	10	24	2	17	8
	(80.0)	(20.0)	(58.3)	(41.7)	(92.3)	(7.7)	(68.0)	(32.0)
Heart Disease	23	3	15	10	24	2	17	8
	(88.5)	(11.5)	(60.0)	(40.0)	(92.3)	(7.7)	(68.0)	(32.0)
Gastrointestinal	24	3	13	11	25	1 (3.8)	17	8
Disease	(88.9)	(11.1)	(54.2)	(45.8)	(96.2)		(68.0)	(32.0)
Epilepsy	20	8	13	12	24	3	17	10
	(71.4)	(28.6)	(52.0)	(48.0)	(88.9)	(11.1)	(63.0)	(37.0)
HIV/AIDS	20	4	13	11	24	2	17	8
	(83.3)	(16.7)	(54.2)	(45.8)	(92.3)	(7.7)	(68.0)	(32.0)
Food Allergies	12	17	10	15	25	2	17	9
	(41.4)	(58.6)	(40.0)	(60.0)	(92.6)	(7.4)	(65.4)	(34.6)
Renal Disease	22 (95.7)	1 (4.3)	14 (58.3)	10 (41.7)	25 (96.2)	1 (3.8)	17 (68.0)	8 (32.0)
Chronic Migraines	21	8	15	10	24	2	17	8
	(72.4)	(27.6)	(60.0)	(40.0)	(92.3)	(7.7)	(68.0)	(32.0)
Juvenile Idiopathic Arthritis	23 (95.8)	1 (4.2)	12 (52.2)	11 (20.3)	25 (96.2)	1 (3.8)	18 (72.0)	7 (28.0)

Table 5

Awareness of Educational Issues

Variable	$M\pm SD$	p
Grade Level		
Undergraduate Student	1.62 ± 1.02	
Graduate Student	1.57±1.13	.92
Educational Specialty Track		
Regular Education/Other	1.65±1.14	
Special Education	1.50 ± 0.76	.74

low, between only somewhat to moderately aware, irrespective of grade level or educational specialty track.

Current preparation methods. Regarding methods used by their program to prepare them to work with students who may have a chronic health condition, nine (42.9%) undergraduate students reported that this topic was addressed within a single course that also addressed other topics; six (28.6%) reported this information was addressed using other methods; five (23.8%) selected multiple answers; and one undergraduate student (4.8%) reported that information about chronic medical conditions was embedded throughout the curriculum in his/her program. None of the undergraduate students reported that they had a single course dedicated to this topic.

For the graduate students, four (57.1%) reported that this topic was addressed within the curriculum of a single course that also addressed other topics; one reported that discussion of this topic was embedded throughout the curriculum; and one graduate student mentioned that a single course was dedicated solely to working with children with chronic health conditions. And one reported that the topic of chronic conditions was addressed through other methods besides having a course on the topic, while none of the graduate students reported that this topic was addressed through multiple teaching methods in their programs.

Regarding educational specialty track, nine (47.4%) students in regular education/other track reported that this topic was addressed within the curriculum of a single course that also addressed other topics; five (26.3%) reported that this information was addressed using other methods; two students (10.5%) reported that information about chronic conditions was embedded throughout the curriculum in their program; two selected multiple answers; and one student in the regular education/other track reported that he/she had a single course dedicated to this topic. For students in the special education track, four (44.4%) reported this topic was addressed within the curriculum of a single course that also addressed other topics; three (33.3%) selected multiple answers; and two (22.2%) reported this information was addressed using other methods. No students in the special education track reported that discussion of this topic was embedded throughout the curriculum in their program or that a single course was dedicated solely to this topic.

Academic opportunities offered by colleges of education. A chi-square analysis was used to examine differences in undergraduate and graduate student responses about their perceptions of whether their program offered academic opportunities that prepare them to work with future students who may have a chronic condition. There was a statistically significant difference between undergraduate and graduate students' perceptions of educational opportunities, $\chi 2$ (1, 29) = 4.15, p = .04. Thirteen (59.1%) undergraduate students reported that they were unsure or no academic opportunities were offered, while nine (40.9%) reported there were academic opportunities offered by their college of education. In contrast, all seven (100%) graduate students reported they were unsure or no academic opportunities were offered to prepare them to work with future students who may have a chronic condition.

Discussion

Similar to prior studies (Bradford et al., 1994; Pufpaff et al., 2015), results of this research indicated that teacher preparation relative to school support for students with chronic health conditions is lacking, both in quantity and quality (Bradford et al., 1994; Clay et al., 2004; Pufpaff et al., 2015). Few teacher preparation programs directly address how school personnel should provide school support for this population of learners. Furthermore, there are widespread misunderstandings about this student population and teachers generally report feeling ill-prepared to meet the needs of this growing population in the classroom setting.

Regarding the first research question, which explored how teacher preparation programs across the country prepare educators to support the school-related needs of students with chronic health conditions, curriculum review findings suggested that most programs embed any dedicated instruction on this topic into special education programming. There are limitations to such an approach; notably, many children and adolescents with chronic conditions are served in the general education setting, often failing to qualify for special education services. Because eligibility for special education services is not guaranteed, or even appropriate, for many children with a chronic condition and, given the general emphasis on inclusion in education today, both general and special educators must be prepared to meet the needs of this student population. Several university representatives who were interviewed erroneously viewed this group as a low incidence population. As more children with chronic illness are surviving and doing well, but still experiencing academic, health, mental health, and social challenges related to their disease, addressing their needs becomes important to ensuring a full and high quality educational experience for children with illness-related needs (Pufpaff et al., 2015). Thus, knowledge and skills regarding needs of children with health conditions should be included in undergraduate and graduate educational experiences. Content on the functioning of children with chronic conditions and their educational needs should be included in stand-alone courses or existing courses based on faculty expertise and experience. If faculty do not have expertise, linking with teaching hospitals and involving guest speakers in courses and program presentations is another way to incorporate this material in teacher preparation experiences.

Placement of curriculum under the umbrella of special education programming underscores the broader issue associated with defining the population of students with chronic health conditions. Interview findings suggested that there is significant confusion about who this population of learners includes; participants erroneously referred to this population of students as "low

incidence," and as including only youth who are hospitalized or served in specialized medical settings. Terminology defining this population is confusing, ranging from special health care needs to medically fragile to other health impaired to chronically ill, and others (Thies, 1999). Even within single terms such as special health care needs or chronic conditions, there is great variation, with no single accepted definition (American Federation of Teachers, 2009), thereby resulting in differences in prevalence estimates and understanding of need.

Given these inherent challenges, it is not surprising that this population has been underrepresented in teacher preparation curriculum. There is a "ripple effect" associated with
inconsistent terminology and misperceptions about the population. When programs perceive that
a population is low incidence, it is difficult to justify separate and distinct programming
dedicated to teaching school personnel about the population needs. Program representatives were
forthright in asserting that, given curriculum demands, including additional content on school
support for students with chronic health conditions would be challenging. The paradox is that
students with health conditions represent a higher proportion of students than many other student
populations addressed in teacher preparation curriculum. Curriculum review findings revealed a
disproportionate allocation of curriculum relative to prevalence when compared to other high
incidence student groups, including students with autism, English Language Learners, students
with mental and behavioral health conditions, and students who are gifted. This is not to suggest
that those particular populations should not be accounted for in teacher preparation curriculum,
but rather to emphasize the relevance of also including content on school support for students
with health conditions, commensurately.

Regarding the second research question, which sought to determine the frequency of teacher preparation programs that explicitly advertise an emphasis on training educators on the schoolrelated needs of students with a chronic health condition, few programs specifically call this out as an area of expertise of specialization within their program descriptions or marketing materials. This finding was consistent with previous literature indicating that teachers do not receive training and are not prepared to meet the needs of children with chronic illnesses (Clay et al., 2004; Selekman, 2017). Educators have highlighted the value of this training for improving children's educational experiences and increasing teacher confidence and abilities to meet the needs of all children in their classroom (Cunningham & Wodrich, 2006; Prevatt et al., 2000). In contrast, to the Olson et al. (2004) findings, participants in this study perceived the needs of children with chronic illnesses to be critical and felt they were ill-equipped to meet needs and required more training to better serve this group. This may be indicative of stirrings of change in the field. Capitalizing on this research, as a type of needs assessment, will help educators move forward in incorporating training for working with children with medical conditions into their curriculum. Thus, a practical implication of this project was that preservice teachers enrolled in the nation's leading colleges of education felt ill-equipped to meet the needs of students with chronic health conditions, and desire more curriculum and preparation in this area.

Limitations

While this research study utilized multiple methods to examine the identified research questions, a primary limitation emerged due to the small sample size of survey respondents. However, findings were consistent with other studies that have examined similar content (e.g., Clay et al.,

2004; Selekman, 2017). Additional methodology limitations were inherent in the curriculum review process, such as the known variation associated with curriculum and online availability and completeness of such content; triangulation and member-checking with interview data helped to validate this process to the greatest extent possible. Furthermore, only 15 of 40 universities participated in the qualitative portion of the study; certainly, potential for bias existed within the interview process based on the respondent's role and position within the teacher preparation program. It is possible that the individual interviewed may not have always been fully versed on the complete breadth of educational programming at the respective university.

Conclusion

Through this research, it has become increasingly evident that while teacher preparation programs do not sufficiently address how to support students with chronic health conditions in program curriculum, the root cause for this underrepresentation is due more in part to larger, system-level issues as opposed to programmatic issues. That is, lacking definitional criteria and prevalence estimates, rigid curriculum demands, and misunderstandings about the population have led to inadequate training for teachers, without ill intention or deliberate oversight. Likewise, curriculum in teacher preparation programming is often guided by legislative mandates, which dictate areas of accountability for future practitioners. The populations accounted for in present curriculum align closely with the populations specifically addressed in, for example, No Child Left Behind (NCLB; now Every Student Succeeds Act [ESSA]), which explicitly acknowledges the student populations accounted for in curriculum, and does not necessarily distinctly acknowledge students with chronic conditions, in particular (ESSA, 2015; NCLB, 2002).

Given the known educational implications and lifelong complications associated with chronic conditions, teacher preparation programs must now catch up to ensure appropriate supports relative to the aforementioned prevalence increases are provided for students with these conditions. This includes prioritizing content in teacher preparation programming, although this may also be contingent upon acknowledgement in legislative mandates, which is likely contingent on prevalence (Pufpaff et al., 2015).

At minimum, an intermediary solution may be to shift how support for students with chronic conditions is incorporated at the university level in teacher preparation programming. Integrating content in this area into general education teacher preparation may provide a more realistic model for preparing the educators most likely, or equally likely, to serve these learners. Universities and colleges of education can begin integrating small steps of change by adding content on school support and best practice for students with chronic conditions into their teacher preparation programming through brief modules, project work, and intentional acknowledgement in existing curriculum. While more is likely needed to truly increase educators' confidence in supporting this population of learners, change must not be delayed while waiting for large scale, system-level changes.

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Author's Note: The authors would like to thank Kirbi Hais, Guylyn Wade, and Amanda Buncher for their study coordination at various stages of this project. Address correspondence concerning this article to Mary Kay Irwin at marykay.irwin@nationwidechildrens.org.