

Creating Productive Futures for Youth and Adults with Intellectual and Developmental Disabilities

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REACHING THE SUMMIT OF SUCCESS



NCCDD
North Carolina Council on
Developmental Disabilities

Preface

The North Carolina Council on Developmental Disabilities funded the Reaching the Summit of Success Project beginning on October 1, 2012. The project's purpose was to learn about the current policies and practices in the state that promoted transition to post-secondary education and competitive, integrated employment for youth and young adults with intellectual and developmental disabilities (IDD). These policies and practices were then considered along with best practices in other states to determine a set of recommendations for the Council to consider as it advances systems change.

Over the three-year period, the project conducted:

- » Informal discussions with individuals and groups
- » Structured interviews with individuals
- » Four regional summits
- » A provider forum
- » Two round-table discussions
- » A state conference
- » A policy seminar
- » A North Carolina ASPE Conference presentation and information gathering session
- » Numerous meetings with the project's steering committee

All of these activities offered personal and professional perspectives on the status of North Carolina's education, vocational rehabilitation, developmental disabilities, and post-secondary education systems. Additionally, numerous individuals with IDD, family members, and the business community offered their perspectives about the programs, projects, and organizations in the state that are high-performing and merit replication, as well as recommendations for improvement.

The project activities also allowed participants to learn about transition and employment, both in NC and nationally. The summits included presentations by content experts, as well as panel discussions featuring state agency representatives, services providers, individuals, family members, and employers. World café sessions promoted a lively exchange of ideas, information and resources. All of these components were also part of the statewide conference that was attended by over 100 stakeholders.

As we approached the end of this project, there were two key changes at the federal level that will have significant policy and practice implications for North Carolina: the CMS Community Settings Rule and the Workforce Innovation and Opportunity Act (WIOA). These set the stage for a more urgent focus on services and supports that are provided in the community and lead to true community participation, as well as on transition from school to employment.

The Reaching the Summit of Success Project would not have been possible without the guidance, engagement, and support of the following people, who generously gave their time and expertise:

- » Beverly Colwell, Department of Public Instruction
- » David Ingram, Autism Society of North Carolina
- » Stephanie Hanes and Alice Farrar, Division of Vocational Rehabilitation Services
- » Chris Egan, Holly Riddle, and Shayna Simpson-Hall, North Carolina Council on Developmental Disabilities
- » Kenji Kellen, Project Consultant
- » Emery Cowan, Sandy Ellsworth, and Joshua Strasburg, Department of Health and Human Services
- » Donna Gallagher, The Collaborative
- » Melissa Little
- » Krystle Bailey
- » Sid Smith and Ron Reeve, North Carolina Business Leadership Network
- » Davan Cloninger, Lifespan Inc.
- » David Test, University of North Carolina, Charlotte
- » Joan Johnson and Lisa Pluff, Beyond Academics, University of North Carolina, Greensboro
- » Kelly Kelley, Western Carolina University
- » Deborah Zuver, University of North Carolina at Chapel Hill
- » Betsy MacMichael, Families First of North Carolina
- » Trudy Hughes, NC Community Colleges

“Participating in this process over the past three years has been incredibly valuable. I have learned a great deal that I am already putting into practice both within my own agency and in our collaborative work with other agencies.”

– State agency representative

Executive Summary

The North Carolina Council on Developmental Disabilities funded the Institute for Community Inclusion at UMass Boston to identify policy and practice changes that will increase transition to post-secondary education and competitive employment outcomes for youth with IDD.

Countless North Carolinians are committed to the value of Employment First, and spend their time advocating; providing services; funding services and supports; teaching children, youth, and young adults; employing people with disabilities; and preparing professionals for careers. The state has participated in the State Employment Leadership Network and continues to participate in systems change work in partnership with the US Department of Labor’s Office of Disability Employment Policy.

For the past several years, North Carolina has attempted to craft an Employment First policy that spans disability and age. A post-secondary alliance is in place whose members offer college experiences to youth with IDD across the state, with one of the largest PSE networks in the country. Additionally, the state has a Business Leadership Network, as well as a growing Project Search program.

Several schools and school districts, such as Cleveland County, are providing work experiences and related services leading to competitive employment, while meeting challenges such as limited transportation options. Vocational rehabilitation counselors and transition specialists are providing seamless services in New Hanover County that prevent youth falling off the cliff from high school to adult services.

Lifespan, Inc. has transformed itself from an organization that paid sub-minimum wages to some of its clients to one that is totally community-based. It is an exemplar of a high-quality and outcome-oriented employment and community support organization.

Finally, the state APSE chapter is one of the largest in the country and has the highest number of staff who have passed the Certified Employment Support Professional examination.

These are just a few of the examples of the promising practices that were identified and observed during the three years of the project.

In spite of these practices, North Carolina is experiencing challenges to the expansion of employment. The recession resulted in higher unemployment throughout the state and the recovery has been uneven. Rates for service provision have not changed in more than 15 years. The majority of adult service providers have not altered their service delivery model to prioritize competitive and integrated employment, in spite of federal legislation and evidence-based practices.

State agency leadership has fluctuated frequently during this project, and we were unable to find a champion within the high levels of state government promoting either transition or competitive employment systems change. Managed care organizations (MCOs) are the locus of control now, and while one or two of these has staff on board with employment knowledge, the competitive employment values are not deeply embedded within the MCO structure at this point in time. Expectations are often low, and family members find it challenging to navigate the transition and employment landscape.

North Carolina has enormous potential for achieving transition to post-secondary and competitive employment outcomes because the state has pockets of excellence that can be replicated and expanded. However, the state will need to adopt new policies to grow and sustain these practices. The recommendations that follow offer guidance on how to do so.

Understanding Employment for Individuals with IDD in North Carolina

In 2014 in North Carolina, 22% of individuals receiving day and employment services through the NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services were in integrated employment services, either individual or group employment. The remaining 78% were engaged in facility-based work services or other non-work services.¹ The National Core Indicators reports that only 18% of individuals served by the Division have integrated employment as a goal in their ISP.²

Individuals with IDD in North Carolina also receive employment services through the Division of Vocational Rehabilitation. The tables below provide a summary of employment outcome data for individuals with IDD for FY2013.³

TABLE 1
Summary Data from the RSA-911 for Individuals with IDD Ages 18-21 (FY2013)

	North Carolina	United States
Rehabilitation rate	51.9%	47.8%
Eligible placement rate (percent of those eligible for services who exit with a job)	33.7%	31.8%
Hours worked at exit	26.3	24.0
Earnings at exit	\$219.90	\$203.11

TABLE 2
Summary Data from the RSA-911 for Individuals with IDD Ages 22-30 (FY2013)

	North Carolina	United States
Rehabilitation rate	56.7%	55.1%
Eligible placement rate (percent of those eligible for services who exit with a job)	37.4%	38.4%
Hours worked at exit	25.6	22.9
Earnings at exit	\$211.05	\$190.04

Employment for individuals with IDD occurs within the context of a state's overall economic climate. At the time of this report, North Carolina's statewide unemployment rate was 5.8%, a significant improvement from the unemployment rate of 9% at the time this project began. Yet the recovery has been uneven, as demonstrated by unemployment rates as low as 4.3% in the Asheville labor market area and as high as 7.1% in Fayetteville.⁴ Statewide, the employment participation rate in 2013 for individuals with no disability that are employed was 71.1%, while the rate for people with a cognitive disability was 20.8%.

Day and employment services and supports are provided through either state or Medicaid waiver funds administered through managed care organizations (MCOs) throughout the state and through the Division of Vocational Rehabilitation. The array of services offered varies throughout the state, and service options also depend on the type of waiver or funding source for the service.

Community provider agencies offer services through contracts with the MCOs and/or the Division of Vocational Rehabilitation. While community providers may be qualified and approved to receive funds through both agencies, many may only be a provider for one of these funders. The capacity of community provider agencies to provide individual integrated employment options varies significantly, with clear pockets of excellence in some areas and others where there are limited options to support individuals in obtaining individual integrated employment.

For a number of years, efforts have been underway to move North Carolina towards becoming an Employment First state. In general, an Employment First state has policies, executive orders, and/or pieces of legislation that identify employment as the first and preferred option for individuals with disabilities. Stakeholders have advocated for an executive order supporting Employment First with little success.

While such an order has not occurred, state leaders have stated that employment is a priority. There are many good reasons to become an Employment First state, but what is most important is the action that a state takes to follow through on the promise of employment.

Today, there is a lack of clarity in North Carolina about good employment practices and outcomes. Many are asking questions about the role of group employment and social enterprises. Specialized employment programs for populations such as individuals with autism are being developed. In forums and roundtables, examples were frequently cited of programs and services that were by some considered to be best practice, yet often lacked opportunities for meaningful inclusion and realization of individual employment goals and aspirations.

Now is a key time to define the outcomes that are expected and the approaches to service that will lead to these outcomes. While the IDD field lacks the comprehensive evidence-based practice that can be found in the mental health arena, information on best practices for individuals with IDD is widely available and should be tapped to outline the practices and outcomes in employment.

Key Themes

While this report breaks down the observations and recommendations, there were a number of themes that crossed all of the project activities:

Innovation and promising practice can be found throughout North Carolina.

There are school districts, local partnerships, post-secondary education programs, and progressive community agencies helping people get their own jobs. Project SEARCH sites and other pockets of innovation exist throughout the state.

State agencies have many committed champions.

Throughout the state agencies, many engaged and committed staff are eager to be part of the solution as North Carolina works to improve employment outcomes for young people with IDD.

Individuals and families want individual employment and full participation in their communities.

While there are, in every state, individuals and families who may want to maintain the status quo, over and over again individuals and families talked about their desire for jobs and meaningful connections and engagement in their communities.

Limited expectations and values are inconsistent with employment and inclusion.

While the steering committee identified family

expectations as a barrier, this issue goes beyond families. Numerous stories were shared about school personnel, community providers, and others who struggle to see the full potential of the individuals they support. In one of the summits, we heard comments from provider staff such as: “These people can’t work in the community. Other people can’t find a job, so why should an employer hire someone with a disability? They belong in a community-based organization. We are ticked off that people want to change the system” and statements indicating that individuals with intellectual disabilities would prefer to be with others like themselves and would not be accepted by employers. Organizations that employ staff that do not possess the values that all people can and should work will not be able to transition to community.

Yet in the same community we heard from a parent who talked about how welcoming people in her small town were. Her son had success at work and in the community.

A consistent vision about what quality employment looks like is lacking.

There is a lack of clarity about good employment practices and outcomes. Models and approaches are cited as promising practices that are neither inclusive nor driven by individual goals and aspirations. The role of social enterprises in the service array needs further examination as more of these businesses are developing in the state.

The complexity of the service system impacts access.

The transition experience varies greatly across the state, as does access to services and supports through the adult service system/managed care organizations. Services vary depending on whether they are state-funded or waiver services, and on which waiver service an individual is receiving. Service providers talked about the differences in policies and rates in different parts of the state. Access to ongoing support in employment is challenging to access, and the transition from VR to IDD services is not yet smooth.

Geographic and socioeconomic diversity must be taken into consideration.

One size does not fit all. As efforts move forward to improve transition and employment outcomes, they must take into consideration the local and regional diversity of the state. This should not mean compromising on expectations and outcomes; it may just mean that different approaches are needed.

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● EXPERIENCES OF INDIVIDUALS AND FAMILIES

At the first meeting of the Steering Committee in April 2013, low parental expectations were cited as one of the major barriers to successful employment for youth with IDD. Access to information and resources about employment throughout the life span was also identified as a major need. Family-focused organizations in NC, such as First in Families, are an essential resource. However, they have many priorities and varying levels of expertise in the area of employment.

The lack of clarity about good employment practices and outcomes also creates challenges for families. They need access to information, resources, and success stories that help illustrate what good employment outcomes look like in order to support their family members on an employment pathway.

In order for families to have the information they need to help their children make choices for their future and to advocate within school systems, it would be beneficial for the state to consider when and how information should be given to families. NC lacks a cohesive and consistent approach to engaging with families as they progress through the lifespan. The Administration on Intellectual and Developmental Disabilities recently funded an initiative called *Community of Practice: Supporting Families Throughout the Lifespan* that is currently operating in five states. While NC is not a participant in this project, the tools and resources developed through this project are available on its website (www.supportstofamilies.org) and include information about employment.

Individuals with IDD attended each of the *Reaching the Summit of Success* events. Like families, they lack access to current, relevant, and consistent information regarding employment and the many options available to them. Without having access to timely information which is specific to an individual's life and choices, the youth may believe that competitive employment or post-secondary education are not viable options for them. Similar to our observations about families, we also did not see an

organized network of individuals with disabilities or a single self-advocacy organization with a competitive employment mission.

Recommendations

- » Several states involved in the Partnerships in Employment Transition Systems Change project (California, Tennessee, and Wisconsin) are holding Community Conversations around their states to share stories, experiences, and build networks that will lead to community acceptance and competitive employment for youth and young adults with IDD. We recommend that the Council fund a similar project. There are areas in the state where individuals are not aware of best practices either in North Carolina or in the country. This lack of knowledge hinders progress toward employment. Community conversations can have dramatic results in bringing together people with disabilities, business people, and families to have honest conversations. They also help to clarify values and build relationships.
www.waisman.wisc.edu/cedd/pdfs/products/community/LaunchingInclusiveEfforts.pdf
- » We recommend that a family coalition be formed. Its sole purpose should be to support and educate other families by providing information and resources, and to build advocacy skills related to transition, post-secondary education, and competitive employment. This coalition would prepare or access materials for families of young children regarding employment expectations; an explanation of benefits and work incentives related to employment; language to be inserted in ITPs and IEPs for outcome- and career-oriented employment services; clear descriptions of the state and federal funding streams and obligations; asset development and financial management; and making informed choices about adult services and post-secondary education. Resources will be needed to support this coalition. While it should be focused on families, it should also work in

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partnership with agencies engaged in the education, transition, and employment systems to develop informational materials.

- » Through the years, the North Carolina Council has advocated and financially supported a self-advocacy network and has experienced challenges with sustaining and growing this network.. We recommend that the Council now collaborate with the Department of Public Instruction and the Post-Secondary Alliance to support a new youth coalition whose purpose is to promote competitive employment of youth with IDD. In doing so, we recommend that the state's Employment First Committee adopt strategies being followed by the Florida Employment First project. In this project, individuals with IDD are serving on all of the committees supporting the project, rather than serving on a separate self-advocacy committee. This allows them to learn about the components that are necessary and how they link together in order for individuals to receive inclusive education and employment. On the Florida project, a paid employee with IDD works alongside Institute for Community Inclusion staff members to translate the policies and documents into materials suitable for non-professionals. In this way, individuals gain systems-change knowledge to advocate for themselves. Organizations that are members should consider how to financially support youth or young adults with IDD to be participating members of the Committee. Their participation and feedback is vital.

● EDUCATION

Like most states, education services are provided locally with state and federal oversight. North Carolina, with a county-based system, has a wide range of educational and transition-focused practices. Standard program options such as the Occupational Course of Study offer the potential for work based learning, but the experiences shared through the Reaching the Summit of Success activities demonstrate that these opportunities are inconsistent across the state. In some cases, there was concern that the two-tiered diploma system did not truly recognize the skills and accomplishments of some students.

There was general agreement that transition needed to start earlier in the schools. Many stakeholders recommend a life-span approach that addresses the developmental needs of children while communicating clear and consistent messages about the value and expectations for work. One idea was to use after-school programs as a way to incorporate discussions about jobs and careers and possibly provide work experience. This is an option that could be considered under Pre-Employment Transition Services required by the federal Workforce Innovation and Opportunity Act (WIOA).

WIOA is creating system changes in NC, particularly between the Department of Public Instruction and the Department of Vocational Rehabilitation, as these agencies will be required to collaborate in funding and providing transition services. It is the intention of this Act that transition will begin earlier in high school and that the vocational rehabilitation counselor will be interacting with high school clients prior to them exiting high school. As the departments roll out their plans for implementing WIOA, it will be important to explain the changes to individuals and families so that they are aware of their rights and services under the act.

Stakeholders noted that Project Search is a very effective approach for transition-age students to learn marketable work and social skills. Since the beginning of the Reaching the Summit of Success project, there has been expansion of sites within the state. However, the numbers of individuals in internships is relatively



“Make sure the community is on board. Build your reputation. So many people would hire someone with a disability if they understood and someone asked them.”

- Nellie Aspel, Cleveland County School Superintendent

small. Several people thought that there should be consideration by state agencies to develop new approaches to internships that are similar to a Project Search model, but would be located in other market sectors and widen opportunities for youth.

Additional promising practices were identified during the project activities:

- » The Cleveland County School District transition program was repeatedly identified as a model that should be replicated. One of the key characteristics of the program is a team-based approach to transition. Once a month, adult service providers and others from the community meet at schools to hear the students present their needs and wants. The input is then factored into the IEP and services. This design reduces siloes and brings the student, providers, and other community members to the table early in the transition process, and helps bridge the transition from school to competitive employment. Also, self-advocacy strategies are part of the curriculum, and students have access to assistive technology such as iPads to assist with instruction. A transition specialist, a job coach, and occupational preparation teachers support the classroom teachers. Students are linked to adult services as early as their sophomore year. Since there is a long waiting list for the Medicaid waiver, this school system tries to get the youth on the list as soon as possible.
- » Several individuals noted that the CIRCLES project at UNC Charlotte offers great promise for improving the interagency coordination that is necessary for post-school outcomes. This grant-funded research project supports interagency collaboration at the administrative leadership level, the school level, and the individual team level, with a goal of improving post-school outcomes for students. Results from this project should be used for replication within all of the diverse regions of the state.
- » Community provider partnerships exist in a

number of areas throughout the state. Through these partnerships, schools purchase employment services from local community providers in order to ensure that young people have opportunities to gain work experience and are prepared to transition from school into employment. These partnerships vary from county to county and provider to provider, but do have the potential to connect students with the community-based work experiences that schools often find challenging to provide.

- » Schools were also identified as instrumental in providing families with information and communicating expectations. The LifeCourse framework developed by the University of Missouri highlights the importance of providing information across the lifespan. Given the length of time children and their families are engaged with schools, schools are uniquely positioned to provide high-quality information and resources that set expectations and support young people on a pathway to employment. There do not currently appear to be any standardized materials that are given to families through the education system.

Over the course of the project, family members shared stories of teachers who had made all the difference and other teachers who had very limited expectations for their family members. Families expressed concern that the state is losing many qualified teachers because of low pay. Teacher preparation and training was identified as an area to be addressed.

Recommendations

- » Each school should have a transition coordinator. In our interviews with teachers, they noted the benefits of having a coordinator as part of the educational team. The coordinator should attend IEP meetings and should support drop-out prevention and community college partnerships. Classroom teachers frequently do not have the time or expertise to provide the individualized services that many youth with IDD require.
- » Each school should have its own transition fair

each year. These already take place in a number of counties, and were identified as an effective approach to helping young people and their families learn about services, link to employers, and meet other families. Fairs can provide opportunities to share success stories that can be very effective in raising hope and expectations. Outreach should be given to families who have not attended in the past and may have difficulty attending because of work, childcare needs, or transportation barriers. They may need one-on-one assistance. In the Wisconsin Promise state grant, staff is visiting homes to meet with youth and families to ensure that they have information about benefits so that they can make an informed decision about remaining on benefits or choosing employment.

- » Eliminate self-contained classrooms. Students with disabilities benefit from being with their peers, learning from them, and being supported by them. Students without disabilities also learn about the talents that their peers have and how they contribute to the classroom. These lived experiences are necessary for community inclusion; it starts in the classroom, then to the workplace, and leads to a full community life.
- » The Workforce Innovation and Opportunity Act speaks to the importance of student involvement in transition services, including gaining self-advocacy and self-determination skills. The Department of Public Instruction (DPI) should be developing protocols to ensure that student-directed IEPs are in place throughout the state. An excellent resource for self-directed planning was developed by the University of Oklahoma:
www.ou.edu/content/education/centers-and-partnerships/zarrow/trsition-education-materials/student-directed-transition-planning.html
- » Continue and expand replication of Project Search and similar internships, mentorships, and apprenticeships that provide work-based learning for students with IDD, particularly those opportunities that offer payment.
- » Concerted and coordinated efforts should be taken by DPI and family organizations to provide information about rights to education and employment early in a child's life.



- DPI should develop a one-page fact sheet for families that explains the importance of expecting and advocating for competitive employment outcomes for their children. This easy-to-understand fact sheet should be given to families at the time the first IEP is written.
- Families need information about work incentives for those receiving or contemplating applying for Social Security disability benefits. By the time students begin the transition discussion at 17 or 18, they are already conditioned to accept segregated work or non-work and are fearful of losing benefits. The discussion about work, benefits, and asset development should start much earlier, ideally 6th grade or even before. Early intervention--in this instance, employment early intervention using a strength-based framework--can help shape attitudes and goals. These conversations should be taking place within schools.
- » High schools should partner with community colleges. With the elimination of the Compensatory Education program in the community college system, it is expected that there will be growth in career-oriented opportunities within the community college system. Partnerships between high schools and community colleges can provide opportunities for young people to access career-focused education and training, setting the stage for future employment. Opportunities for dual-enrollment programs can be invaluable. Dual-enrollment opportunities with the post-secondary education programs in the state should also be considered.

» Teachers and transition coordinators should receive professional development to prepare them for assuming their expanded responsibilities in the transition process. Curriculum should include subjects such as developing relationships with the business community; negotiating and arranging for work experiences, job shadowing, and internships; conducting environmentally-based assessments such as discovery and situational assessments; understanding person-centered planning processes; benefits planning; social skills development; and incorporating self-advocacy into the standard curriculum. Legislative advocacy to address pay scales for highly skilled teachers should be a part of the disability community's agenda for the coming year.

» The state should consider a transition endorsement, which would require that educators receive the specific knowledge and skills necessary to address the transition needs of youth with disabilities. Several universities now offer such a course of study including:

- University of Massachusetts Boston
www.doe.mass.edu/edprep/advisories/TSEguidelines.pdf
- Lesley University
www.lesley.edu/endorsement/transition-specialist/
- Bowling Green State University
www.bgsu.edu/education-and-human-development/school-of-intervention-services/special-education/graduate-programs-in-special-education/secondary-transition-certificate.html

» For teachers who are not able to access additional professional development, the DPI should consider funding a teacher-coaching model. In Wisconsin, the DPI funded five coaches with expertise in transition and employment. They fan out through their respective regions providing support to teachers in their respective LEAs. This practice was initially a pilot program in nine schools. Employment outcomes from these schools far surpassed the schools that did not have coaching assistance, with 62% of the youth exiting these schools obtaining paid employment. Consequently, the DPI made the decision to build up its own capacity to provide this support.

» Engagement with teacher preparation programs throughout the state is essential. Parents and students repeatedly spoke about the impact that teachers with high expectations made in their lives. They talked about the impact newly trained teachers entering the workforce from special education college programs focused on inclusion and innovation are having on their futures.

● POST-SECONDARY EDUCATION

North Carolina has a large and vibrant network of post-secondary education programs. We heard from many students enrolled or recently graduated from these programs. They and their family members enthusiastically talked about the positive and enriching experiences they had attending college, particularly the socialization with their peers. North Carolina's post-secondary programs offer youth exiting high school an exciting and enriching path to adulthood. The Post Secondary Education Alliance (PSEA) is a strong advocate for both existing programs and continued expansion of this important option.

North Carolina's Community College system is transitioning to a career pathway model (a requirement of WIOA) whereby students will be required to enroll in classes that develop knowledge, skills, and abilities related to future careers. Since the former compensatory education system allowed for students to remain in the community college system for an unlimited amount of time, the 58 colleges in the system are in the midst of important changes. However, these changes will result in a robust statewide network of post-secondary institutions that will build the capacity of the workforce, including those with IDD.

Recommendations

» The cost of post-secondary education is a barrier for many students. The PSEA has been engaged in discussions with the DVR related to accessing VR funding for post-secondary education for individuals with IDD. Currently, VR will only fund PSE in a student's final semester of college. DVR may want to consider funding other coursework that is directly aligned with the student's vocational goal. It is important that this dialogue continue, along with other efforts to braid funding in order to decrease financial barriers to post-secondary education.

- » Several students and family members expressed concern about not having a job when they exited college. While this is not a unique phenomenon to students with IDD, we recommend that the PSE programs expand career counseling and employment services for students. Beyond Academics at UNC Greensboro (www.beyondacademics.uncg.edu) is an exemplar in this area and a number of other PSE are also making significant progress.
- » With the discontinuation of compensatory education services within the community college system, there is an opportunity to restructure the services offered through community colleges to focus on inclusive job-driven training opportunities that lead to better employment outcomes for individuals with IDD. These training opportunities should be time-limited and aligned with the employment opportunities available in the various regions of the state.

● DEPARTMENT OF HEALTH AND HUMAN SERVICES

There have been numerous changes in leadership and other personnel at NC DHHS since Reaching the Summit of Success began. This mobility is of concern since the Department has lost consistency and traction,



particularly regarding Employment First policy development. However, several new staff members are familiar with employment policy and have voiced support for making policy changes that are needed to improve the state's outcomes.

Recommendations

- » DHHS should develop a users' guide to long-term care services, including employment services, that explains the process of connecting to both waiver-funded and state-funded services that are essential for those in need of employment supports.
- » DHHS should clarify and communicate its long-term support funding policies to families and providers. Several individuals commented about the need for more funding for these types of supports that contribute to job retention and lack of clarity related to the sequencing of VR and IDD services.
- » Each person receiving IDD services is required to have a person-centered plan. The department should annually monitor how this plan is being developed, as the process should conform to evidence-based or best practices. Included in the review should be goals, objectives, and outcomes. When there is a discrepancy, the plan and/or service should be revised.

● VOCATIONAL REHABILITATION

With the passage of WIOA, VR will be expected to provide additional services to youth in transition. From our observations, there are state agency staff that have developed exceptional working relationships and understand the policies of each agency. These individuals will now be expected to design new models of coordinating, delivering, and funding education, post-secondary, and competitive employment services for youth with disabilities. They will also be required to integrate the expectations of WIOA into their plans.

Recommendations

- » Examine and clarify the policy and practice for reopening a VR case.
- » Clarify HIPPA policy. Several parents stated that they learned their son or daughter was offered VR services but turned them down. While ultimately

this is the individual's decision, family members are essential partners and can be valued allies in the process of supporting young people to go to work. Students and families should be fully informed of the benefits of VR services and this counseling should occur before the student becomes eligible for VR services. The discussion about VR should begin at the IEP meetings when the student reaches the age of 14 and annually thereafter.

- » The student should be able to receive employment supports while engaged in post-secondary education. Often a student's employment while in school may be the individual's first job and provide an important foundation for future employment.
- » VR counselors should continue to employ environmentally based assessments such as situational assessments, volunteer work, and paid employment. Information gleaned from high school work-based learning, work experiences, job shadowing, summer youth employment, and other employment-related activities should be factored into the VR counselor's decision-making, particularly regarding whether additional assessments and evaluations are warranted.
- » In partnership with the Division and Medicaid, address sequencing of services to insure appropriate and timely VR referrals and access to long-term employment supports.

● INTERAGENCY COLLABORATION

While many of the areas addressed above include interagency collaboration, there are additional opportunities that exist in NC where interagency engagement is essential.

Recommendations

- » WIOA specifies that Pre-Employment Transition Services (PETS) available to youth with disabilities include self-advocacy, career exploration, and work-based learning, as well as counseling on post-secondary education and work readiness. It will be important for advocates to work closely with the DPI and VR to learn how WIOA will be implemented within high schools and to also track post-employment outcomes. Ensuring that there is equity of access to PETS across the state is essential.

- » Encourage school districts and local state agency personnel to become familiar with the Memorandum of Understanding between DPI and VR. During our visit to New Hanover County, we learned that the transition coordinator and the VR counselors met together to review the MOU and then developed their own local agreements to specifically outline roles and responsibilities of both parties. These individuals did not look at the MOU as a policy that is put on a shelf, but as a working document that can result in effective and efficient service delivery. Their approach to coordinated service delivery is a model for the entire state and should be promoted by the Council, DPI, and VR as a strategy for implementing the transition provisions within WIOA.
- » Sequencing of services is a key issue in North Carolina and needs to be addressed in an interagency context, including VR, Medicaid and the Division. The State Employment Leadership Network has shared a model with NC. Alaska also offers an example of a detailed framework to support an integrated model of service delivery with ongoing employment support for those who need it.
- » A variety of people spoke to the importance of having an online single point of contact where individuals, family members, employers, and professionals can receive information that is linked to other sources, is updated to reflect changes in state and federal policies and practices, and provides tools they can use in their daily lives. Tennessee Works' website, www.tennesseeworks.org, is an excellent example of how a state can collect and present pertinent information for a

“There are so many things going on in the Charlotte area that I didn't know anything about. After this meeting I'll be calling some of the people I met today to talk with them more about helping my son.”

–Charlotte Regional Summit Attendee

variety of stakeholders. The DD Council should consider expanding its own website to include information similar to that in Tennessee or fund an entity to do so.

● COMMUNITY-BASED ADULT SERVICE PROVIDERS

One of the challenges facing youth with IDD is that there are a limited number of providers that offer competitive employment services. Many organizations provide facility-based work, non-work, and supported employment. We did not hear of any initiatives or policies that encourage the leaders of these organizations to change their business model to one that prioritizes competitive employment.

There are large providers scattered throughout the state. Some of these include supported employment in their array of options, although the supported employment programs tend to be add-ons and smaller in comparison to day habilitation or work adjustment. Several individuals commented that the providers have not been pushed by the state to do anything differently. Once again, for the state to change, state agencies will need to make it clear that what the agencies will pay for is competitive, integrated employment.

We also heard that attention should be paid to the capacity of the adult services system. It is difficult for providers to recruit and retain staff, which is disruptive to those receiving services. There is a great need in North Carolina for an investment by the state in capacity building. Training is almost non-existent and relies primarily on the two annual conferences hosted by North Carolina APSE. This is not sufficient for building skills and competencies of employment services staff.

In the final year of the project, we interviewed several adult providers and toured one of them. These interviews, supplemented by comments during the summits, reveal that there is not a statewide commitment by providers to offer competitive, integrated employment services. As with any business, the directors of these organizations need to ensure their financial stability and viability. Without a fiscal analysis followed by state rate restructuring, the providers are unwilling to change the way they conduct business. We

“By moving away from self-contained classrooms, we have elevated expectations and saved money to pay for other services.”

-Special ed teacher

learned that there is a wait-and-see approach, primarily regarding the home and community based service settings rule and how it will be enforced.

The state developed the self-assessment required by the Centers for Medicare and Medicaid Services (CMS), which was piloted in June and then rolled out in July without extensive input and discussion. Some advocates believe that these actions are reflective of the beliefs of state agency leadership towards the importance of full integration of individuals with IDD within the community. As the Division moves forward with its transition plan to meet the requirements of the CMS Community Setting rule, NC will need to build capacity in the provider community.

There are a number of agencies engaged in promising practices in the state. One example is Lifespan. This organization services serves over 1,200 children and adults in 20 locations around the state. Several years ago, its board of directors made the decision to eliminate sub-minimum wage certification and convert its sheltered workshop.

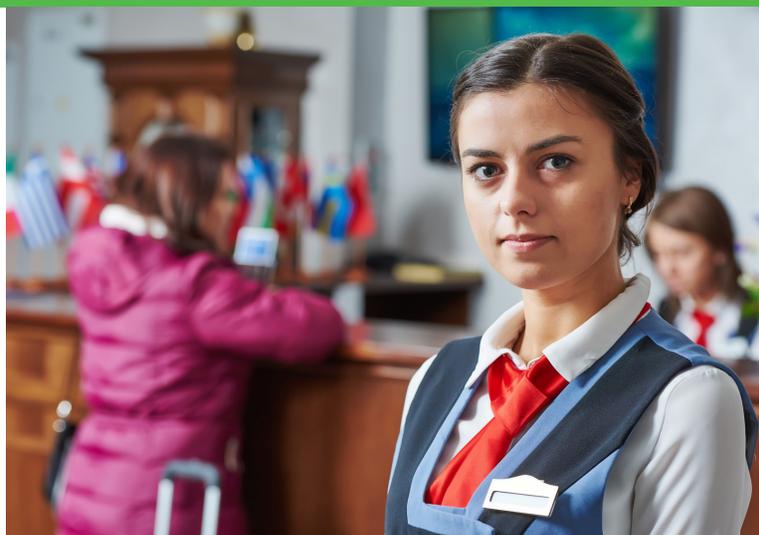
The organization prides itself on delivering services that individuals want. It expects its staff to be nimble and comfortable with change. Lifespan is supported by a variety of funding sources, including school districts, VR, supported employment funds, waiver services, public and private grants, and fundraising. To continue to grow the business, the CEO, Davan Cloninger, expects that Lifespan will be involved with mergers and acquisitions. It has expanded its client pool to include individuals with mental health needs, and it is using the Dartmouth Individual Placement and Support model to provide employment services.

Lifespan invites young children, teachers, and parents to visit to help build expectations that the child will grow up to become employed in the general workforce. The organization's leadership recognizes the importance of training employment services staff and expects these

staff to have excellent marketing skills. She views these staff as being account executives that are comfortable within the business world as well as in the disability services sector.

Recommendations

- » Technical assistance is needed to help providers transform their service models. Attention should be paid to these types of services in rural communities.
- » Rate restructuring, while difficult in challenging economic times, is essential when combined with a fiscal impact analysis. Without adequate rates, innovation will be limited and providers will continue to be challenged to hire and retain qualified staff. Integrated into this work must be a clear definition of best practices and a funding strategy to ensure provider stability as individuals become more independent and require less support.
- » Assisting individuals with significant IDD to locate a job and career of choice requires a highly skilled job developer. Training in person-centered planning, job development and job carving, job creation, and supporting micro-enterprise is sporadic or non-existent in certain parts of the state. As North Carolina seeks avenues for its investment in employing individuals with disabilities, training and technical assistance should be provided in each region of the state and available to teachers, transition specialists, and service provider staff in a consistent and regularly scheduled manner.
- » The Council should consider funding a demonstration project that will explore a new approach to delivering transition and employment services to youth and adults with IDD. There are several organizations around the country that have sprung from the vision of delivering services that are exclusively community-based. One example is Shared Support Maryland Inc. (www.sharedsupportmd.org/index.html), which provides its support, based on person-directed planning and organizational change, to individuals with severe disabilities. It does not operate day programs, sheltered workshops, or group homes. Rather, individuals choose what they would like to do during the day, evening, and weekend. It serves 50 individuals in the Central Region of Maryland.



Other organizations doing similar work are Values Into Action, operating in New Jersey and Pennsylvania (<http://valuesintoactionnj.org/history-and-mission/>), and Work Link in San Francisco (www.transcen.org/index.php?option=com_content&view=article&id=254%3Anewday&catid=1%3Alatest-news&Itemid=1#) These three organizations share a philosophy of person-directed services. They do not have overhead associated with large buildings and equipment, and have small numbers of staff, which allows them to be flexible, efficient, and outcome-oriented with their service delivery.

BUSINESS ENGAGEMENT

Relationships with businesses are essential to any effort to improve transition and employment outcomes. The NC Business Leadership Network is well established and has many major employer partnerships. There are a number of initiatives such as Project SEARCH that have effective business engagement.

Going forward it will be important to consider strategic expansion of business partnerships. Key issues to consider in this expansion include:

- » Development of a business engagement strategy that meets the need of a diverse array of businesses including small and medium-sized companies.
- » Use of a job-driven approach to business engagement--developing strategic training and placement efforts to align with the hiring needs of businesses.
- » Building on the relationships that already exist

“We are banging on the door. Sooner or later the state and federal government will be smart enough to listen to us. Change needs to occur here.”

-Employment staff member

between human service agencies and local businesses, and transforming those relationships from ones based on charity and philanthropy to ones with a focus on how these agencies can be a source of qualified workers.

- » Providing appropriate training for employment support professionals to ensure that they are integrating best practices in job development into their work with businesses.
- » NC may want to consider strategies to promote a coordinated approach to job development such as the Progressive Employment Model led by VR in Vermont.

● AN ADVOCACY AGENDA

The Reaching the Summit of Success project team had the opportunity to meet many dedicated, committed, and hard-working individuals, family members, educators, service providers, and state agency personnel. Many of them have already embraced a number of items discussed in the report. Yet there continues to be a need for leadership and advocacy.

- » It is imperative that members of the General Assembly and the Governor’s Leadership Team be informed about services for individuals with IDD and the federal laws and funding sources that support community inclusion. It will be helpful to have a cost analysis that documents the savings that states realize when people are competitively employed rather than relying upon the state for services.
- » We recommend that the Council arrange for a legislative briefing on employment of individuals with IDD. Several individuals commented that without the awareness and commitment of legislators, it would be difficult to enact substantive changes to the education and adult services systems. Due to the Council’s numerous initiatives over the past few years that have examined and demonstrated transition to employment, such as asset development and financial literacy, microenterprise development, and the Reaching

the Summit of Success project, the Council is in a strong position to provide recommendations to the legislature. These recommendations can address compliance with Olmstead and the Americans with Disabilities Act regarding inclusive education and adult services. It can also detail best practices, among these, the need for highly trained teachers and service providers in career development and business engagement. To attract and keep qualified personnel, compensation must be addressed. North Carolina employment data is included in this report, which can be used for such a briefing. Youth who have exited college with employment and family members should be involved in planning for and participating in this briefing.

- » Indicator 13 data reports the percentage of youth with IEPs aged 16 and above with an IEP that includes appropriate measurable postsecondary goals. This date along with the VR and IDD data, should be reviewed annually with the directors of state agencies, with a goal of identifying steps that will lead to continued improvement. The responses should be posted on the Council’s website and distributed to its listserv. The Council has responsibility for encouraging collaboration and coordination, and is uniquely positioned to facilitate interagency dialogue and cooperation in improving transition services.
- » The Council should request that the lead state agencies jointly issue a statement that the state, in compliance with Olmstead, will require that each adult service provider agency providing services to individuals with disabilities increase the number of individuals served in the community by a defined percentage (e.g., 15% per year for the next five years).
- » The Council should also request that the IDD agency identify a date to “close the front door” of the sheltered workshops for transition-age youth.

Other areas that require attention but do not fall into a certain category are listed below.

- » Transportation came up frequently as a barrier to community employment. The Council should consider developing a transportation resource guide that describes a variety of ways that individuals get transported to work, including direct service staff transporting individuals, individuals paying for taxis, and reimbursing friends, coworkers or others using wages or work incentives. The Council should consult with the Community Transportation Association of America, which works to remove barriers to transportation experienced by people with disabilities and senior citizens. <http://web1.ctaa.org/webmodules/webarticles/anmviewer.asp?a=23&z=2>
- » Financial well-being and asset development were raised primarily in the context of conversations about public benefits. There is a need to reframe the discussion for individuals considering work to one that focuses on financial well-being rather than protection of benefits. For individuals and families with the financial means, the ABLE Act can also provide a new resource for supporting individuals in reaching their goals.
- » Managed Care Organizations (MCOs) are now involved with employment. We heard from many stakeholders that most MCOs do not employ staff with a background in employment or with an understanding about the supports required for many individuals with significant disabilities to live and work within the community. The MCOs should actively recruit and hire staff with an employment background. These organizations are an integral force in systems change. Aside from the Rocky Mountain MCO, we did not hear of other MCOs that were attuned to the importance of post-secondary education and employment. MCO staff members would benefit from receiving training in the values, philosophies, and rights of people with IDD to community living, education, and work. One commenter said that an MCO representative should be required to attend IEP

meetings to better understand students' needs and their path to employment.

- » There are numerous coalitions in North Carolina that meet to address education, community, and employment outcomes. However, there have not been significant policy or practice changes during the past several years. Some individuals noted that this is due to a lack of progress toward results-based interagency collaboration. Others believed that state agency leadership need to fully commit to the vision of competitive employment for people with IDD. Still others point to the fact that provider rates have not increased in over 10 years, making it almost impossible to deliver individualized services to people with IDD, particularly those with very significant disabilities. Finally, others said that the entire system of employment should be mapped and redesigned so that it is seamless from the individual's perspective as the funding and agencies come together to provide a time-efficient and employment-oriented experience.



Conclusion

The Reaching the Summit of Success project provided a unique opportunity to engage with a wide range of stakeholders over a three-year period, listening to and learning from North Carolinians about their experiences in the transition from school to employment. This report frames out strengths and opportunities, as well as challenges and recommendations.

As this report is being finalized, there are many in North Carolina who are already taking steps forward to address some of its recommendations. Other recommendations will need to be addressed as NC moves forward in implementing WIOA and the state's transition plan for community settings.

Comprehensive systems change will require leadership commitment from state government and the engagement of a multi-individuals with IDD and their families as part of a stakeholder coalition to support, guide, and monitor that change. Leadership in state government and by stakeholders is needed if young people are to transition from school on a career path that will afford them opportunities for self-sufficiency and to be productive and engaged members of their communities.

Systems change is a complex set of mechanisms that all need to move at the same time for the practices and policies to stick. It begins with the value that all people can work. This value needs to be owned by all of those who are involved in the change.

A value or policy statement is not enough, however. A series of objectives, timelines, and resources needs to be put in place with data collection and analysis to track performance and to ensure that changes are being made in every region.

Employment is a civil right for all individuals, including those with disabilities. The best practices and recommendations in this report will provide guidance to North Carolina as the state moves forward.

(ENDNOTES)

- ¹ Butterworth, J., Winsor, J., Smith, F. A., Migliore, A., Domin, D., Timmons, J. C., Hall, A. C. (2015). *State data: The national report on employment services and outcomes*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- ² NCI Adult Consumer Survey Outcomes, North Carolina Report, 2013–2014 Data (2014).
- ³ Statedata.info
- ⁴ US Bureau of Labor Statistics. Local Area Unemployment Statistics. October 2015.





