There are few constants in life but one has always been the "graduation ceremony." Whether one attends a graduation at a kindergarten, a high school, a medical school or a law school, the atmosphere is the same: an auditorium filled with parents who have two points of pride etched on their faces—a recognition of their child's accomplishments and an enduring belief that the ceremony means a brighter future and better things to come for their child.

For students with significant disabilities and their families, what is often etched on a parent's face is not the sudden recognition, but the growing resignation that this day marks the end of the best their child's life would ever become. The following day all the supports the School provided would be gone and for many the supports provided in the adult service community were still unknown. Simply put, the adult service community is fundamentally unprepared for the depth and breadth of challenges graduates (with special needs) face each and every day. Graduation for too many isn't the dawn of a new horizon, but rather a grey twilight.

Todd Reeves
Executive Director
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Transition-age Youth with Complex Needs Entering Adulthood:

Transforming a Grey Twilight to A New Horizon

Adults with Complex Transitions (ACT) Research Study

United Way of Allegheny County 21andAble Project
Paula Rule Consultant

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- Judy Barricella, Director of Disability Connections
- Rick Boyle, Special Projects Director, Epilepsy Foundation of Western Pennsylvania
- Tina Calabro, parent, advocate and disability writer
- Judy Cohen, parent, advocate and Executive Director of the Jewish Women's Foundation
- Al Condelucci, CEO of UCP Pittsburgh
- Jeremy Gilchrist, coordinator of Employment Opportunities Project, Blind and Vision Rehabilitation Services of Pittsburgh
- Carolyn Glass, parent and community advocate
- Mary Joe Guercio, Director of Community Training and Development, Community College of Allegheny County
- Lori Guttman , parent and community advocate
- Liz Healey, Executive Director, Pennsylvania Education Advocacy and Leadership Center
- Jeni Hergenrender, attorney, Disability Rights Network of Pennsylvania
- Nancy Murray, President of the Arc of Greater Pittsburgh at ACHIEVA
- Dr. Jonathan Pletcher, M.D, Children's Hospital of Pittsburgh
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Executive Summary

Youth who have significant medical, intellectual, communication and/or behavioral challenges, face challenging barriers to living meaningful adult lives after they leave the supportive environment of the educational system at age 21. These individuals are often excluded from community day activities, employment, volunteer opportunities, community living arrangements and transportation solely because of difficulty meeting their needs in these environments. They have been "left behind" in the lively self-determination and self-advocacy movements within the disability community because of limited communication skills. They struggle to find appropriate medical care as they transition from the pediatric to the adult system. Without well-articulated opportunities and supports that meet the challenges faced by these individuals as they exit the educational system, many live restrictive adult lives with limited choice and limited freedom.

In September 2012, the United Way of Allegheny County's 21andAble project launched as an initiative to identify the systemic barriers faced by these young adults in transition and to design a set of viable pilot projects and policy initiatives that will challenge obstacles, build the capacity of service providers, and dramatically improve quality of life for youth in transition. Overseen by disability rights attorney Paula Rule and guided by an advisory committee of 17 professionals and parents, the "Adults with Complex Transitions" (ACT) project analyzed data and examined research on this segment of the transition-age population, convened young adults, parents, program providers and others for face-to-face discussions, and conducted interviews and online surveys with hundreds of constituents.

The result of the ACT study is an indication of the size and characteristics of target population and of the barriers that prevent these individuals from engaging in everyday community life -- or even participating in disability-only offerings such as day programs and supported housing. In addition to highlighting issues that require new kinds of thinking -- such as how to expand residential options, lifelong learning education opportunities and wellness – the study also revealed a widespread need to inform and educate individuals, families and service providers about existing, effective, but underutilized approaches to various problems.

Every year, approximately 100 individuals in Allegheny County - with the most severe and complex disabilities - graduate from their school-age services. Throughout the state, hundreds of their counterparts do the same. Whether they live in urban centers, small towns or rural areas – whether they graduate this year, next year or five years from now -- all face the end of appropriate, responsive and well-coordinated support and services.

The seven-month research phase of the ACT study led to the identification of six major areas where change and growth are needed in the adult disability service systems in order to serve youth with complex disabilities in transition. These areas are:

- Expanding the use of available life-planning tools (including legal tools) so the challenges of adulthood are adequately anticipated and planned for;
- Establishing opportunities for individuals to continue building functional communication skills so they may participate more fully in decisions about their own lives;
- Building the capacity of day options to support individuals with the most complex needs;
- Educating medical professionals about individuals with complex needs;
- Increasing and improving residential housing options; and,
- Promoting a "living wage" for caregivers in order to lower turnover

Creating a set of viable pilot programs and policy initiatives to address the identified needs was the next step of the ACT study. With continued and detailed input from the advisory committee and survey respondents, the following pilot projects emerged as having the greatest promise of effecting change for the current population of graduates:

1. Collaborate with disability organizations on an awareness campaign that informs service providers about the unique needs of transition-aged individuals with severe and complex needs to begin to create a service environment that meets their unique needs .

2. Collaborate with a partner - such as the University of Pittsburgh Law School -to educate individuals, guardians and adult service professionals about the legal options available for supportive decision-making across all systems environments.

3. Collaborate with educational organizations to promote the use of supported self-advocacy and decision-making as part of the Individualized Education Plan transition process during the school years.

4. Collaborate with healthcare organizations to promote self-advocacy for young adults with severe and complex needs, including the development of an individualized supportive advocacy plan.

5. Advocate for the implementation of more medical home models in Allegheny County which may allow primary care physicians to bill for time spent on indirect medical support services like coordination, research and referral.

6. Advocate for changes in Medicaid and private insurance billing codes which would enable physicians to bill for the extra time it takes to serve individuals with complex needs or individuals who need longer time to communicate on their own behalf.

7. Expand community-based day options for individuals with complex needs, including expanding the capacity of current structured programs to meet the needs of this population through additional support, creative programming, and collaboration with other private and public entities.

8. Promote increased quality of direct supports to individuals with complex needs by supporting a living wage for direct care workers.

9. Improve service coordination for young adults by implementing person-centered planning strategies and tools.

Our community must begin to address quality of life issues for youth with severe and complex disabilities. The Commonwealth of Pennsylvania is poised to do more to reach the vision that all Pennsylvania youth and young adults with disabilities will successfully transition to productive, participating, adult citizens empowered to recognize their talents, strengths and voices with access to resources that promote full participation in the communities of their choice.

Statement of the Problem

Individuals who have significant medical, intellectual, communication and/or behavioral needs face unique and difficult challenges to achieving meaningful lives after they leave the supportive environment of the educational system. These individuals are excluded from community day activities, employment, volunteer opportunities, community living arrangements and transportation due to present systems' inabilities to meet their needs. Although the disability community has moved leaps and bounds in self-determination and self-advocacy movements, individuals with complex disabilities are often left behind due to the their communication and intellectual challenges. They struggle to find appropriate medical care as they transition from the pediatric to the adult system of medicine. Without an adult system of supports that meets the multiple and complex challenges faced by these individuals, they will live in residential environments which are too restrictive and will live restricted lives without choice.

The educational community has been required to address transition issues since the implementation of the Individuals with Disabilities Education Act (IDEA) in 1990. The individualized education plan process (IEP) customizes educational support for students to help them maximize their independence skills before leaving the educational system. For students with complex transition needs, the need for structured and intense support continues beyond the high school years, and in most cases continues for the rest of their lives. The legal mandates which drive school services do not exist in the adult disability system, and many individuals find themselves leaving school and entering adulthood without services or plans for the future. These individuals often end up living at home with their aging parents who continue to provide support until they are no longer physically, emotionally and financially able. At this point, the individual's placement in an even more restrictive setting is almost a certainty.

Research and anecdotal reports indicate that the issues faced by transition-age youth with complex needs in Allegheny County and throughout Pennsylvania have not been thoroughly examined. The ACT study is a first step in that important work.

Background on the ACT project

The Adults with Complex Transitions study began in 2010 when a focus group of professionals and parents was convened by the Allegheny County Department of Human Services, to identify the most serious barriers to meeting the support needs of adults with complex disabilities. In September 2012, the United Way of Allegheny County asked this focus group to serve as the advisory committee for a study of the most-challenged transition-age youth. The study, named “Adults with Complex Transitions” (ACT), is part of the United Way’s *21andAble* initiative, which seeks to improve the transition from school to adult life for youth with disabilities. The ACT study focuses on youth and young adults between the ages of 14 and 29 with the most complex disability support needs. The purpose of the study is to identify the population and the challenges the population faces, and propose initiatives to address those challenges.

Background on Adults with Complex Transition Needs

Nationally, about 32.5 million people of all ages in the United States live with severe disabilities (12% of the population*). Approximately one to two percent of all school-aged youth nationally have complex support needs.* The national population of individuals age 14 to 29 with complex support needs is not tracked.

The Pennsylvania Department of Education describes students with complex support needs as those who:

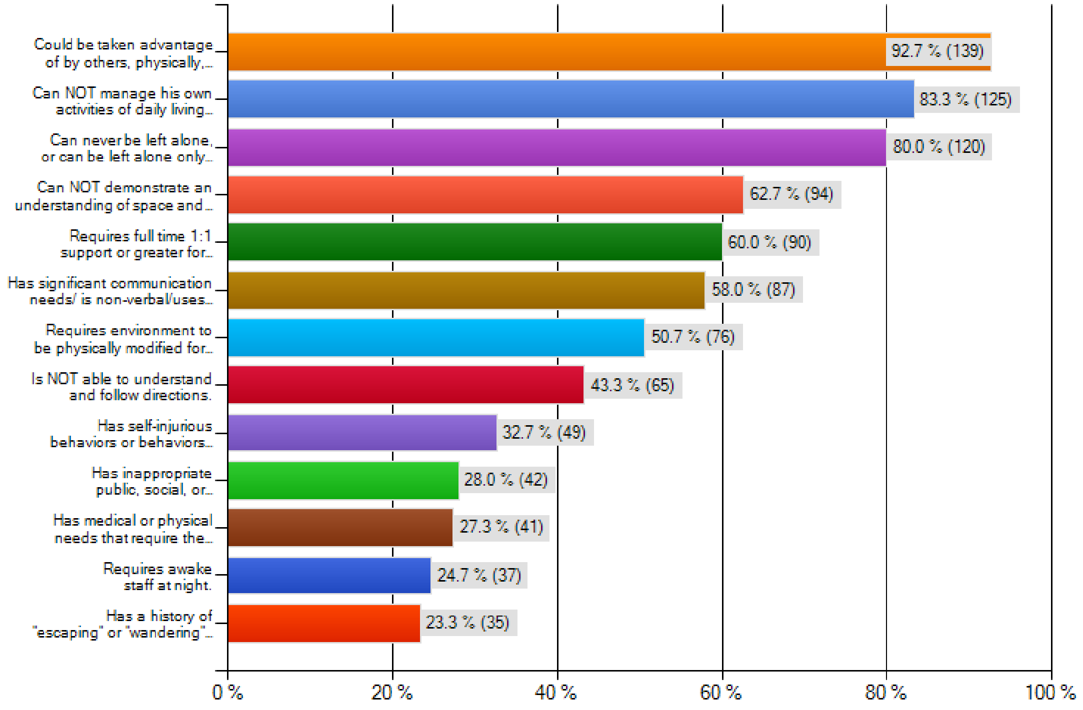
- are most often assessed with the Pennsylvania Alternative State Assessment (PASA) rather than the Pennsylvania State Standardized Assessment;
- may include students who have intellectual disabilities and/or who may need life skills support, multiple disabilities support, autistic support or physical support; and
- may require augmentative communication systems and assistive technology in order to access and/or participate and progress in, learning.

According to the 150 respondents to the ACT “Individual and Guardian” survey, the top five characteristics of these individuals are:

- could be taken advantage of by others (92.7%)
- cannot manage activities of daily living (83.3%)

- can never be left alone, or can only be left alone for a short time (80%)
- cannot demonstrate an understanding of space and time (62.7%)
- require 1:1 support or greater for health and safety (60%)

The full range of functional needs of this populations is represented by the chart below:



SECTION I: DEMOGRAPHICSPlease list or describe your/this person's functional needs as completely as possible. Please check all that apply, and elaborate with comments at the end of this question.

In Allegheny County, 97 new graduates are expected to leave the educational system in June 2013 with a need for intensive support from the Office of Intellectual Disability. Many of these individuals also have significant medical or mental health challenges. Of the 97 graduates in 2013:

- 32 will require intense levels of support costing in excess of $30,000 / year;
- some will require annual support costing $70,000/year or more;
- 4 will have their budgetary needs approved by the County; and,
- 28 will not receive public funding through the Medicaid waiver program to meet their basic support needs, but will be added to the growing "emergency" waiting list for Allegheny County

Currently there are 264 people on this list in Allegheny County, 164 of who are between the ages of 18 and 29.However, getting off the "waiting list" and getting a Medicaid waiver can still be inadequate to meet individual needs. System capacity has not kept up with the need. More than half of the 62 Allegheny County service providers who completed the ACT "Provider Survey" stated that they could not or do not provide support adequate to address significant medical or physical needs. Between 15% and 40% of providers say they cannot provide adequate support to individuals with significant behavioral challenges.

The gap between the need and availability of support services grows wider as funding for programs dwindles and even more individuals enter the adult system.[1]

Methodology

This study was guided by an advisory committee of 17 professionals and parents who met every 4 to 7 weeks over a period of 8 months to discuss progress and provide direction, support and expertise. Professional members of the advisory committee included those who work in advocacy organizations, direct service and the Allegheny County Department of Human Services. Several methods were used to measure the target population and to elicit input from stakeholders regarding challenges and solutions. A "Community Dialogue" of 50 stakeholders was held to discuss local and national initiatives. Personal interviews were held with 17 provider or advocacy organizations and 25 individuals or guardians. Data about the population in question was provided by the Allegheny County Department of Human Services and the Home and Community Service Information System (HCSIS). Topical research was conducted on current initiatives and "best practices" in health and wellness, residential options and day programs. Surveys for educators, adult service providers and individuals with complex needs and their guardians were disseminated broadly through electronic and social media. [2]

Systems capacity challenges and priorities

The existing publicly funded system of support for individuals with complex disabilities is stretched thin. Support coordinators in the County's Office of Intellectual Disability have large caseloads which hamper the development of truly supportive relationships with clients. Because there is a "waiting list" for individuals to receive Medicaid waiver funding for intellectual disability supports, service providers are being asked to provide service to individuals with complex disabilities without a commensurate increase in funding for programming or more and/or better training for their staff. The ACT study identified several critical challenges within the support systems in Allegheny County and across the state:

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[1] According to one provider, three individuals must move off of the current Consolidated Waiver for each new person. The growing burden on families to provide the supports gap over a lifetime is not sustainable. Our current state and county system for individuals with intellectual and multiple disabilities is failing to address even the most basic needs of young adults leaving the children's system of support, and the state has no comprehensive, viable, sustainable initiatives to address this issue.

[2] Due to the confidentiality and privacy mandated by the Health Insurance Portability and Accountability Act (HIPAA) and the Federal Educational Records Privacy Act (FERPA)comprehensive lists of individuals and their families could not be obtained. Heavy reliance was placed on social media outreach and on provider's dissemination of the surveys to their internal mailing lists. Individuals who do not use social media or structured county services were not able to be reached.

- Cross-system coordination and sharing of information
- The level of Medicaid coverage for essential support such as nursing, therapy and behavior support *past* age 21 (when child Medicaid enrollment ends)
- Respite and in-home help with activities of daily living
- Wage and level of training of direct support workers
- Capacity of Existing day programs
- Individuals with complex needs develop self-determination and self-advocacy skills;
- Community residential options for the population
- Public transportation options
- Transitions from pediatric to adult health care
- Publicly-funded services.

The ACT survey revealed some overlapping areas of concern between individuals and service providers, as well as some disparities in perceptions of challenges. Providers listed their top three priorities as:

- Funding for supports and services
- Wages and recruitment for and continuous training of direct support staff
- Day activities or programs

When individuals and guardians were asked to express their level of interest in potential projects, they showed strong interest in almost all areas of identified need for this population:

PROJECT TYPE	Very Interested	Somewhat Interested	Not Interested
Medical transition from pediatric to adults providers	75.3%	20.5%	4.1%
Wage of caregivers	72.8%	23.8%	3.4%
Supportive decision-making tools and options	70.5%	23.5%	6.0%
Training for EMS	67.4%	35.8%	6.8%
Accepting disability as natural and enhancing natural supports	67.1%	29.5%	3.4%
Better inter-agency coordination and case management	67.1%	25.3%	7.5%
New residential options	61.2%	27.2%	11.6%

Re-framing supports by functional level of need	60.5%	27.9%	11.6%
Expanding model community programs	56.9%	32.6%	10.4%
Addressing barriers to existing day program options	53.8%	28.3%	17.9%

The top three priorities for individuals and their families were: medical transition; wages of caregivers; and, understanding supportive decision-making options for adults. However, it is clear that there is strong interest in ALL of the issue areas presented. Even among the "lowest" priorities for individuals and guardians, more than half of respondents were "very interested" in initiatives which addressed the issues.

Funding and Public Policy challenges and priorities

Through surveys, interviews and research, the ACT study shows the need for legislative advocacy regarding the following public policy issues through:

- Support the "End the Waiting List" campaign[3] for Medicaid home- and community-based disability waivers;
- Increase the funding cap on the Medicaid "Person/Family Directed" (P/FD) waiver. The current cap is inadequate to fully fund the needs of the individuals with complex needs;
- Create more Medicaid waivers or other public funding sources of for people with complex needs;
- Mandate a living wage for direct service providers and increase standards of professionalism;
- Allow Medicaid payment for adult therapy, such as speech, physical and occupational for individuals without a Medicaid waiver; and,
- Make home- and community-based living, rather than institutional placement, the "default" for individuals with complex needs.

Recommendation Summaries

The United Way 21andAble ACT advisory committee makes the following recommendations for addressing the identified barriers facing transition to the adult system of supports and services

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[3] Medicaid Home and Community Based waivers are Medicaid state level programs which "waive" the necessity that supports and services be delivered in an institutional environment. 42 U.S. C. section 1915.

for young adults with complex needs. These recommendations are intended to address the needs of individuals and their families, as well as the needs of providers of disability supports and services:

- Provide information and education about life planning tools for transition, including educational, legal and coordination tools
- Provide information and education about enhancing individual’s communication capacity for better self-determination
- Expand community day opportunities
- Provide information and education for adult medical providers regarding the needs of this population
- Increase and improve community residential housing options for this population
- Promote and support efforts to provide a living wage to direct care workers

1. *Recommendation: Provide Information and Education about life planning tools for transition, including educational, legal and coordination tools*

   A. United Way could support a concentrated and sustained effort to educate all providers - including school, human service and medical providers- about the transition challenges of young adults with complex needs leaving the educational system by:

      i. Creating an informational packet for school based individualized education teams to supplement the already existing United Way 21andAble “Top Ten Checklist” will recommend a graduation project instructing students to develop a “letter of intent” life planning document to take with them after graduation and share with all adult providers;

      ii. Partnering with a local public or an approved private school, to develop and disseminate an informational packet, a brochure, a video and a public service announcement directed at educating physicians and other health care providers about the transition needs of this population.

   B. United Way could sponsor an initiative to educate individuals and families about legal options for supported decision-making, guardianship and its alternatives, and long term living planning. United Way could partner with a local law school, disability advocacy groups, financial planners, attorneys and social workers to provide public sessions, webinars and videos regarding these issues.

C. United Way could sponsor an initiative to increase understanding of person-centered planning tools such and Microboards, or Self Directed Service Corporations[4]

2. *Recommendation: Provide Information and Education about enhancing individuals' communication capacity for better self-determination:*

    A. United Way could develop and disseminate training videos made by speech pathologists that specialize in Augmentative and Alternative Communication, sign language specialists, and other communication therapists to educate service providers and care givers to maximize communication.

    B. United Way could identify and collaborate with stakeholders and communication specialists to develop a strategic plan for providing ongoing speech and language support into adulthood, addressing funding and sustainability recommended activities.

    C. United Way could develop and disseminate an enhanced communication plan form to be used by all who serve individuals with complex transition needs. The plan would, ideally be attached to their ISP, their medical record, and any other pertinent human service document.

    D. United Way could collaborate with existing transition health care initiatives such as the Children's Hospital "CHANGE" project to include individuals with severe communication challenges on their consumer boards exploring the use of adult "communication partners" in this environment.[5]

3. *Recommendation: Expand community day options*

    A. United Way could partner with a local community to create daytime volunteer, work and leisure activities for people with complex needs. This effort would necessitate identifying an existing structured adult day program interested in collaborating to create more community centered, individualized day options.

    B. United Way could support expanding the capacity of existing structured day programs to address the needs of individuals with complex needs by:

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[4] "Microboard" is a copyrighted term of the Vela Microboard Association of British Columbia and David and Fay Weatherow of Manitoba, Canada. www.communityworks.info.

[5] For more information about "communication partners, see
http://www.mencap.org.uk/all-about-learning-disability/information-professionals/communication/communicating-people-learning-
and
http://www.speechpathology.com/articles/communication-independence-model-for-people-1468

i. Collaborating with existing day program providers to develop fiscally sustainable models that would enable them to support individuals with the most challenging direct care needs;

ii. Creating a more consumer-driven, enriching program of choice of daily activities; and,

iii. Supporting and monitoring a directed public information initiative to clarify current Medicaid rules regarding overlapping services.

4. *Recommendation: Provide Information and Education for adult medical providers regarding the needs of this population.*

5. *Recommendation: Increase and improve community residential housing options for this population by partnering with stakeholders to access and develop welcoming communities for all.*

6. *Recommendation: Promote and support efforts to provide a living wage to direct care workers by*

   A. Collaborating with local universities to create certificate programs for direct care workers in specific areas –salary increases for workers could be tied to the number of "certified" skills they have. Development of degreed or certified programs would enhance the professional status of direct care workers and encourage more of them to think of this as a career and not just a stepping stone.

   B. Partner with local universities to recruit existing students in related fields for direct care giving. Develop a centralized data base, housed at the university, which would contain job descriptions for families who need direct care support workers, and would allow families to access information about interested students from Physical, Occupational and Speech Therapy programs, Rehabilitation programs, and Psychology and Education programs

RESEARCH RESULTS AND DISCUSSIONS

1. *Recommendation: Provide Information and Education about life planning tools for transition, including educational, legal and coordination tools.*

A. United Way could support a concentrated and sustained effort to educate all providers, - including schools, human service providers and medical providers, - about the transition needs challenges of young adults with complex needs leaving the educational system.

Specific outcomes for transition-aged students have been a mandate since the passage of the Individuals with Disabilities Education Act in 1990 (IDEA). [6] In Pennsylvania, transition assessments, services and supports begin at age 14. This period of transition is the bridge between education and adult life; a time for planning and exploring life options. The Pennsylvania Department of Education (PDE) - Bureau of Special Education (BSE) publishes many resources to help parents, students and educators navigate the maze of options. The Pennsylvania Technical Training and Assistance Network (PaTTAN) website houses this information for ready access.[7] Students with complex support needs and their families, however, require additional guidance, as they leave the educational system.

Families struggle with additional challenges such as how decisions will be made, where they will live, how they will manage their medical support and what their daily lives will look like. United Way could create one or more toolkits to address these informational challenges.

United Way 21andAble has created a “Top Ten Checklist” for IEP teams and recognizes the need to develop and disseminate supplemental tools such as checklists, packets of information, and online resources that address the unique transition of young adults with complex needs and that are nimble and relevant.

One recommended set of tools would be used by IEP teams to address the transition process in age-specific steps with recommendations about when to address certain issues. This tool would culminate in a “graduation project” for students to develop a “letter of intent” life- planning document to take with them after graduation and share with all adult providers. This document could contain everything that future service providers and care givers need to know about the individual, including hopes, wishes and dreams. This “letter of intent” would be stored in an electronic format, such as a flash drive, along with important medical and other information about the individual, to be used by all service providers, including medical providers.

This period is unique in our history. As a community, we have never before had so many young people with complex needs transitioning out of youth services. Our entire community must be educated about this issue. United Way could partner with one or more existing stakeholders such as an educational stakeholder, local university departments of education and law, Children’s’ Hospital’s “CHANGE” program, the Department of Health, the Center for Medicaid Services, the Pennsylvania Health Law Project, the Consumer Health Coalition, and the Disability Rights Network, to develop and disseminate an informational packet, brochure, video and public service announcement for providers of health care services.

Public law 101-476, Title 20, United States Code, section 1400 et seq.

[7] http://www.pattan.net/category/Resources/PaTTAN

Another set of tools could be used by individuals and their families to better understand how legal decision-making options change when a youth becomes an adult. As youth with complex needs become adults, they automatically attain legal independence and have the full and complete right and responsibility to take control of their lives, make decisions and make mistakes. Parental guardianship for minors automatically ends. No "declaration of independence" is needed. This legal reality is often emotionally difficult for parents of youth without disabilities, but for parents of youth with complex needs, it presents significant challenges and anxiety. Understanding the legal options for supportive decision-making for the young adult with complex needs can ease some of this anxiety and create a strong transitional foundation. [8],[9]

While guardianship may be an appropriate tool for some families, for others, it is not. In fact, full legal guardianship can be considered by some a barrier to self-determination. It is critical for families and individuals to understand their options and alternatives, and to receive direct support in the execution of the appropriate legal documents.[10]

Ninety four percent (94%) of ACT individual survey respondents indicated they were either "very" or "somewhat interested in efforts focusing on legal and practical options that enable family members to stay involved with supportive decision-making. [11] Many commented that their sons or daughters would need a legal guardianship due to their levels of disability, but the family could not afford the cost. Almost every parent interviewed, when asked about the Health Information Portability and Accountability Act (HIPAA) said they believed the law was detrimental to implementing quality, coordinated medical care for their adult child due to the communication restrictions. Families expressed frustration in navigating these legal issues, and a desire for affordable, easy-to-access guidance. By supporting initiatives to disseminate information about legal decision-making options, United Way will help individuals maximize their right to self-determination that is balanced with support that protects their health and safety. Current advocacy organization such as PEAL, ACHIEVA, the Pennsylvania Health Law Project and the Disability Rights Network offer potential collaboration opportunities with ongoing initiatives. United Way could collaborate with local law schools to provide education, such as clinics, trainings, and videos about legal options. Furthermore, United Way could offer, affordable life planning and legal support for families of young adults with complex needs.

Each of these tools could focus on creating understanding of adult systems of support, maximizing self-advocacy skills and establishing an individualized plan to address any adult system barriers. The outcome for this project could be that every student in Allegheny County

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[8] For the specific legal rights and responsibilities that change at ages 18 and 21, see Appendix 4A.

[9] In Pennsylvania, a person may qualify for a guardianship if his ability to receive and evaluate information effectively and communicate decisions is impaired to such a significant extent that he is partially or totally unable to manage his financial resources or to meet essential requirements for his physical health and safety. See 20 Pa. Consolidated Statutes Chapter 55 and Disability Rights Network publication "Guardianship in Pennsylvania"

[10] Some of the many legal and practical alternatives to guardianship can be found in Appendix 4B

[11] See Appendix 1C(ii) for chart and parental comments.

will be forwarded the information through identification in the Office of Intellectual Disabilities Individualized Service Plan (ISP) process, thereby ensuring that each of these students and their families have access to the tools.

B. United Way could sponsor an initiative to increase understanding of person-centered planning tools such as Microboards, or Self Directed Service Corporations

Nowhere is the complexity of transition more evident than when dealing with the issue of "cross-system" supports coordination. There is no comprehensive framework for providing support to individuals who may have dual diagnoses of mental health and intellectual disabilities, or medical frailty and intellectual disability. Funding for adults with complex diagnoses comes from multiple state and federal resources including the state departments of Public Welfare, Education, and Labor and Industry. Coordination between these departments is weak to nonexistent. An intimidating maze of regulations and paperwork challenges even the most astute individuals, advocates, parents and providers.

Each system has specific types of services they provide, and specific rules and regulations regarding the delivery of those services. The priority of the "supports coordinators" within any of these systems is to ensure compliance with local, state and federal regulations. Each provider or payer system operates within its own silo. True person-centered planning and supports coordination fall by the wayside for individuals who need to access more than one system at a time, or who may have a need or a want which is simply "not covered".

Individuals and their families are looking for better coordination either by changing the way communication occurs within existing systems, or by creating personal support networks that do not rely on the existing structure.

Providers surveyed ranked "improving supports coordination" and "increasing use of tools to improve person-centered planning" as among their LOWEST priorities. Individuals and their families presented a much different perspective. More than 92% said they were either "very" interested or "somewhat" interested in efforts to improve supports coordination[12]

The Self Directed Service Corporation (SDSC), also known as a Microboard, is a possible coordination model that many states are successfully supporting as an alternative to state or locally funded support coordination. A SDSC is a small group of committed family and friends who join together to support one individual with a disability by creating a non-profit organization. The critical requirements of the Self-Directed Service Corporation concept are:

- Development and maintenance of an active, diverse and fully engaged citizen- based circle of support (Board of Directors)
- Retaining all possible elements of control

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[12] See Appendix 1C(v) for chart and parental comments

- An unencumbered focus on the identity, needs and express wishes of the person who is supported

The SDSC exists to provide support and empowerment to one person. It is not a form of guardianship and does not take any legal rights away from the individual.[13] It may or may not become a service provider, depending on need. [14] While the legal and administrative details of setting up a self-directed service corporation can be cumbersome, a successful one can revolutionize a person's life. According to Ruthie-Marie Beckwith, Ph.D., the director of the Tennessee Association of Microboards, the value of setting one up is "immeasurable". A testimonial from the organization's website supports this view:

> "Bobbie's Way, Inc." began in 2003. The 30-year-old woman was living in a group home, where she was frequently unhappy and expressing her frustration in an inappropriate way. After going through the PATH (Planning Alternative Tomorrows with Hope) process, and forming her own self-directed service corporation, Bobbie now lives in her own apartment, has her own full time staff, volunteers at the local ARC, plays bingo, is exploring pet ownership, and learning to do her own shopping. She has discovered her talent for crafts and earns her own money. Her mother proclaims that Bobbie has never been happier.[15]

Many states have used SDSCs, or Microboards, with varying degrees of success[16]. According to Amy Stabano, director of the Texas Microboard Association, the key to success is raising money to support a local or state level collaboration.

In Pennsylvania, a SDSC is an authorized service for funding by the Department of Public Welfare (DPW), Office of Developmental Programs (ODP). [17] The Pennsylvania Developmental Disabilities Council awarded a three-year grant to study and administer SDSCs to the Pennsylvania Health Law Project in 2005. The grant was not re-issued. Pennsylvania currently has a Microboard association that does not receive any state funding and is therefore minimally active. [18]

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[13] However, as a legally incorporated business, it MAY be designated as the legal agency guardian for the individual if guardianship is appropriate. One parent in Virginia has had her daughter's self-directed service corporation appointed as legal guardian.

[14] From "Self Directed Supports Corporations: A Presentation by the Pa. Health Law Project", by David Gates and Grace Egun

[15] From the Tennessee Association of Microboards and Cooperatives, Inc., website: http://tnmicroboards.org/modules.php?name=Content&pa=showpage&pid=27

[16] A list of these states and their Microboard Association websites can be found in Appendix 4E

[17] On July 1, 2007, the Pennsylvania Department of Public Welfare, Office of Developmental Programs, issued Bulletin # 00-07-04 regarding the use and funding of Microboards or SDSCs. In the bulletin, Deputy Secretary of DPW, Kevin Casey, stated that "The purpose of this bulletin is to provide an overview of a Microboard©, its concepts and principles. In addition, this bulletin will clarify the requirement of Administrative Entities (AE's) to contract with qualified Microboards© for the provision of mental retardation services and supports, and to work in cooperation with them to meet the needs of individuals within the Pennsylvania Mental Retardation System"

[18] www.pamicroboardassociation.org/

The Tennessee Association of Microboards is one of the most successful in the country with more than 60 active SDSCs. The director, Dr. Beckwith, attributes its success to committed parents and professionals and ongoing support from state and local funding sources. Over time, Dr. Beckwith envisions a self-sustaining organization whose costs are covered by individual SDSC's membership dues.

If properly supported, Microboards and SDSC's can be person-centered creative solutions to the fragmentation of service delivery for adults with complex transition needs.

United Way could initiate efforts to educate individuals and families about creating Microboards or Self Directed Service Corporations by sponsoring half- to full-day trainings on Microboards/SDSC with Dr. Beckworth from the Tennessee Association of Microboards as keynote speaker.

2. *Recommendation: Provide Information and Education about enhancing individuals' communication capacity for better self-determination: Supporting the voices of individuals with complex needs.*

In a 1962 speech to the House of Representatives, President Kennedy outlined four consumer rights: "the right to safety," "the right to be informed," "the right to choose" and "the right to be heard."[19] Despite the recognition of fundamental rights for all citizens, individuals with significant communications challenges struggle to exercise true self-determination and choice in their daily lives. The very concept of self-advocacy requires individuals to actively communicate their decisions and preferences.

Effective communication skills are essential to self-determination and self-advocacy. Everyone can communicate in some way, and everyone-- with proper support--can participate in the choices which affect their daily lives. Individuals with any degree of disability have a basic right to affect, through communication, the conditions of their existence. [20]

In the last two decades, school systems have put significant effort into teaching and supporting communication skills for students with complex needs. Self-determination constructs such as self-awareness, decision-making, self-advocacy, self-evaluation and communication are built into IEPs.[21] Self-determination assessment tools for transition-age students are yielding

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[19] " Empowerment Through Self Advocacy" https://fp.auburn.edu/rse/trans_meida/08_Publication/06_Transition

[20] In 1992, National Joint Committee for the Communicative Needs of Persons with Severe Disabilities "Communication Bill of Rights", See Appendix 7 for a full and complete list of the Bill of Rights. .

[21] The University of Oklahoma, Zarrow Center for Learning Enrichment, https://www.ou.edu/content/education/centers-and-partnerships/zarrow/self-determination-assessment-tools/air-self-determination-assessment.html

measurable scores in the areas of autonomy, self-regulation, psychological empowerment and self-realization. Communication skills are addressed as an integral part of these assessments.

However, upon leaving the education system, there is no systematic structure to replace these supports. Once students with complex needs graduate, the role of the educator disappears. The expertise to enhance self-determination and communication skills is lost.

It is worth noting that almost ninety-five percent (94.7%) of the ACT "Individual or Guardian" surveys were completed by "a person answering on behalf of youth/young person with a disability" rather than the individual with the disability him- or her-self. Clearly, families struggle with implementing self-determination even in their own home environment. More than half of the families surveyed (58.05%) answered on behalf of an individual with significant communication needs, who is non-verbal or who uses augmentative or alternative methods of communicating. Almost ninety three percent (92.7%) reported that the individual could be taken advantage of by others.[22] These statistics show a need for life-long communication support for individuals with complex needs in the interest of their own health and safety.

United Way could support initiatives and collaborations between individuals, speech and language pathologists, rehabilitation specialists, and service providers that will create sustainable opportunities for life-long development of communication skills. Specific recommendations include:

- Collaborate with local individuals, families and Augmentative and Alternative Communication specialists, sign language specialists and other communication specialists to develop and disseminate a communication enhancement "plan" that can be attached to ISPs, medical records and other pertinent documents. Additional tools and training to aid providers in appropriate implementation the plan could also be created.
- Address the topic of communication development in existing programs such as group homes and adult day programs. Identify group homes and day programs as participants. Purchase a sufficient number of communication devices such as iPads for use by multiple users in each environment. Provide training to all staff and consumers on establishing communication systems with the devices. Collaborate with stakeholders and communication specialists on a strategic plan providing ongoing speech and language support into adulthood. Address funding and sustainability issues in such a plan.
- Create and enhance existing opportunities for young adults with complex needs to participate in self-advocacy , political or social groups with the use of communication partners

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[22] See Appendix 1C(i), detailing the functional needs of those surveyed.

3. *Recommendation: Expand community day options*

A. Expand the capacity of existing residential and day programs for individuals with complex needs by clarifying existing Medicaid service definitions regarding overlapping services.

Cost is the primary reason day program operators give for not providing extra services such as nursing, therapies and behavior support to individuals with complex support needs. Allegheny County providers have long operated under the assumption that the primary way to provide these services is as an expense within their overall operating budgets. This assumption stems from a perceived prohibition in Medicaid against paying for “overlapping services” (i.emore than one service at the same time).

The impact of this perceived prohibition against “double dipping” cannot be underestimated. Individuals have been denied placements in existing day programs or they have gone without essential services such as nursing and therapies. Individuals have been denied paratransit services due to their need for nurses or aides on the bus. Some providers apply a temporary solution of not billing for their own program while the person is receiving other discreet services. Such “patchwork” solutions are unsustainable and unfair to both providers and the individuals they serve.

The ACT study, in collaboration with service providers and government entities, has discovered that the perceived Medicaid policy against “double dipping” is a misinterpretation. While Medicaid does have specific prohibitions against certain types of services being delivered at the same time, this prohibition is not comprehensive. Service definitions for Home and Community Based Waivers for individuals with intellectual disability state that there are NO restrictions as to when certain “discreet” services such as nursing, behavioral support and therapies can be delivered. The services which MAY be delivered at the same time as other services are listed in the chart below:

Service	General Policy	Consolidated Waiver page #	ISP Manual page #
Assistive Technology	No limits on the overlap with other services	107	31
Behavioral supports	May overlap but may not duplicate other waiver services	109	33
Education Support Services	No limits on the overlap of Education with other services.	59	36
Nursing services	No limits on the overlap of nursing services with other	91	57

	services		
Therapy	No limitations on the overlap of Therapy Services with other services.	94	87, 89, 91, 92, 93,87

The Allegheny County Office of Intellectual Disability and the Pennsylvania Office of Developmental Programs are working to uncover the exact source and nature of the misinformation, and to correct the misperception that two Medicaid funded services cannot be delivered at the same time. The ACT steering committee encourages the Allegheny County Department of Human Services to collaborate with an advocacy organization such as the Pennsylvania Health Law Project, ACHIEVA or PEAL, to disseminate correct information regarding this issue to all service providers, individuals and families in Allegheny County. The ACT steering committee recommends that an advocacy organization such as The Disability Rights Network (DRN), the Pennsylvania Health Law Project (PHLP) or the Parent Education Advocacy and Leadership (PEAL) center monitor the dissemination of the corrected information at 3, 6, 12 and 18 months to ensure that it reaches consumers and the providers.

The implementation of the appropriate and accurate Medicaid policies regarding the provision of overlapping services promises to have a significant impact on the lives of individuals with the most complex disability needs living in Allegheny County.

B. Create, improve and enhance community-based opportunities for individuals with complex support needs

In 1999, the United States Supreme Court's Olmstead decision guaranteed the rights of individuals with disabilities to receive community-based services. Although Olmstead was primarily about de-segregating residential institutions, the principal behind the decision warrants a look at other areas of life where individuals with complex needs should be less segregated and more included in their respective communities-- via work, volunteering, recreation and leisure. As the Olmstead decision states, segregated activities "perpetuate unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life."[23]

In 2009, President Obama issued a proclamation launching the "Year of Community Living." Although residential institutionalization has decreased over the last 14 years since Olmstead, many individuals with disabilities continue to be segregated from the community during the day.

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[23] http://www.ada.gov/olmstead/

Every major disability advocacy group has accepted President Obama's challenge to make communities more welcoming and supportive for individuals with disabilities:

- The Arc of the U. S. promotes and protects the human rights of persons with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.
- United Cerebral Palsy's mission is "life without limits for people with disabilities." UCP advocates for independence, productivity and full citizenship of people with a spectrum of disabilities.
- The Autism Society of America advocates for inclusion, participation and self-determination in all aspects of life for individuals on the autism spectrum and their families.
- The self-advocacy organization, "Alliance for Full Participation" advocates for dignity, respect and full community participation.
- The Pennsylvania Developmental Disabilities Council prefers to improve disability services by making them available in the context of the systems and supports that exist for all people.

There is little argument that full community inclusion is the gold standard for people with disabilities. How to make this happen for individuals with complex support needs is particularly challenging. The necessity to address safety, health and welfare concerns as the foundation of any initiative is also critical. Individuals, families, communities and service providers must work together to provide safe, stimulating activities in a community setting of individual choice. When communities begin to look at how to reach the "gold standard" of full inclusion, the question must be raised about where the foundation for change will lie.

In the current structure of supported day programming, the current choices are segregated day settings or home-based, individualized support. Neither of these choices is truly inclusive, but each may provide a platform from which to launch more inclusive community options. The principles of self-determination suggest that we should continue to provide a full range of daytime options for individuals with complex needs-- from supported employment, to structured day program, to individualized community-based options.

In fact, individualized community based day options may be most viable for many individuals with complex needs. These are the same individuals who are, at times, turned away from structured day programs because their support needs are so high. These individuals can utilize their home-based direct support workers in the community, providing the 1:1 support that they are unlikely to receive in a structured program.

Many individuals are already using this individualized day option out of necessity. Parents describe why this model works:

> "N" is constantly on the go She loves to move and to go places. She is very social and craves interaction. We looked at 14 or 15 structured day programs and she hated them

> all. Sitting all day in a structured setting would not work. She needs to be watched constantly. The structured programs do not offer enough supervision or enough physical activity. It is taking a lot of trial and error to find the right people to help her in the community and to offer day activities for her, but we are doing it.
>
> ---M., mother of 23 year old with complex needs

> What "E" does every day is dependent on his health. Every day caregivers come, get him cleaned up and out of the house. He requires 2:1 support to go out into the community. Sometimes they just hang out in the neighborhood. They go to the gym, coffee shops, the library…the neighborhood businessmen all know him. They go to the Oliver bath house for a swim. His days are filled with physical and social interaction.
>
> --C., mother of 24 year old with complex needs

United Way could fund an 18-24 month initiative which will identify local community stakeholders willing to partner to create daytime volunteer, work and leisure activities for people with complex needs. This project would involve identifying an existing adult day program interested in creating a more community-based, individualized day option.

C. United Way could support expanding the capacity of existing day programs by helping them develop fiscally sustainable models of support for individuals with complex needs.

The Individuals with Disabilities Education Act (IDEA) mandates that all students with disabilities be educated in the "Least Restrictive Environment" (LRE). [24] What constitutes the least restrictive environment for a student is individualized. Even with the push toward inclusion in regular schools and classrooms for students with disabilities, special classrooms and schools are also available. While these environments would be considered more "restrictive" in general, they may be the most appropriate environment for the student to make progress. The educational model continues to support a full range of placement options for students with disabilities.

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[24] "Least restrictive environment" (LRE) means that a student who has a disability should have the opportunity to be educated with non-disabled peers, to the greatest extent appropriate. Should the nature or severity a disability prevent the student from achieving academic goals in a regular education setting, then the student would be placed in a more restrictive environment, such as a special school, classroom within the current school, or a hospital program. Generally, the less opportunity a student has to interact and learn with non-disabled peers, the more the placement is considered to be restricted.

In the same vein, while it is important to support community-based day options that welcome with any type or degree of disability, it is also important to support fiscally sustainable, structured day options that address the health and safety needs of the most fragile individuals.

For many individuals with medical frailty, the absence of a structured day program with medical support means isolation at home with a medical service provider and no opportunities to interact with other people. According to educational terminology, this describes a medically “homebound” placement, which is considered more restrictive than a placement in a private school which specialized in disability support.
Helping existing day option better serve the most medically fragile or most behaviorally complex individuals so they may leave their homes and participate in a setting outside the home—even if it is segregated—can serve as a catalyst for increased community access.

Eighty two percent (82.1%) of the “Individual” survey respondents stated that addressing medical and behavioral barriers to full participation in existing day program options was either “very important” or “somewhat important.[25] Programs should be required to meet the needs of the individual rather than the individual needing to meet the requirements of the program for participation.

It is clear that individuals want options. The ACT advisory committee recommends continuing to support a full continuum of day options for individuals with complex needs with the belief that each option is a step towards building more inclusive communities.

4. *Recommendation: Create and support efforts to increase the career stability of direct support workers by paying them a living wage and offering professional development opportunities*

One of the greatest challenges to providing community support for people with complex needs is finding and retaining qualified direct support workers. They are the backbone of the long-term care system. Their jobs require them to help individuals with basic health and self-care needs. These are the individuals who change diapers and clean up toileting accidents. They feed people who cannot feed themselves. They may be slapped, punched and bitten by those for whom they care. They push wheelchairs and do multiple position changes for large adults. They chase after individuals who wander into traffic. They help people gain skills, participate in community life, develop social relationships, make decisions and become more independent. Direct Support Workers must be patient and compassionate while dealing with extremely complex and challenging situations.

The work force that provides these services is underpaid and often poorly qualified, leading to frequent turnover and understaffing. Policy makers and provider organizations must support a

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[25] See Appendix 1C(vii) for chart and comments.

stable, competent, adequately compensated workforce of direct support workers. Doing so ensures the quality and continuity of services for people with complex needs. [26]

In its policy statement for the 112th Congress, United Cerebral Palsy urged lawmakers to:

- Ensure adequate funding so that Direct Support Workers are paid a living wage, including appropriate benefits, at the same level of pay and benefits that states provide for staff working in state-operated programs.
- Require states to develop and implement a plan to address all relevant components that drive the crisis, including low wages and reimbursement rates, high turnover, and inadequate training;
- Require state and federal minimum wage increases to be reflected in state reimbursement rates for services;
- Support authorizing legislation and continuing financial support to provide pre-service and in-service training and other relevant educational opportunities for Direct Support Workers to meet the diverse needs of individuals with disabilities; and
- Implement programs for the direct support labor market to increase the pool of Direct Support Workers and improve recruitment, retention, training, and supervision.[27]

Failure to address these issues will continue to result in a sub-standard quality of care for individuals who rely on Direct Support Workers every day. Paying these workers a living wage makes direct care an attractive career choice instead of a temporary, short-term job.

The director of one day program makes the point very clearly:

> On a whim, I decided to apply for a job at a local fast-food market. They were going to pay me $10.30 an hour plus limited benefits to make sandwiches… fried egg sandwiches, turkey sandwiches. I am the director of a day program that supports individuals with complex physical and cognitive needs. I can only pay my direct support staff $8.10 per hour.

The hourly wage for Direct Support Workers in Allegheny County is below the “living wage” for most families. *“Living wage” is typically defined at an average of $13.00 per hour,* or higher for individuals supporting a family.[28] Direct support workers in Allegheny County earn an average of between $9.00 and $15.00 per hour. Healthcare support workers earn an average of $12.21

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[26] See Joint Position Statement of the AAIDD and The Arc of the United States, www.aaidd.org/content_54.cfm?navID=11

[27] http://www.ucp.org/public-policy/legislative-agenda/programmatic-agenda/critical-agenda/direct-support-workers

[28] For a complete chart of Allegheny County living wage determinations, see Appendix 4D

per hour, while non-medical personal care workers earn an average of $10.01 per hour [29] generally with no benefits.

Turnover of direct support workers and vacancy rates are statistically significant. One source reports annual turnover rates of 35% to 70% are not unusual.[30] The National Council on Disability (NCD) estimates the size of the workforce to be 625,000, the vacancy rate at 6% to 17 %, and the turnover rate at 52 % per year. [31] Ninety six percent (96.6%) of individuals responding to the ACT survey said that they were either "very interested" or "somewhat interested" in seeing this issue resolved:

- "Retraining exhausts already tired parents who desperately want quality care for their adult children and are exhausted as well due to intensive parenting responsibilities."
- "This is probably the biggest factor in the high turnover rate. Also, low pay does not attract individuals who are actually qualified to deal with complex needs."
- "The pay for these valuable people is woefully inadequate."[32]

Across the nation, this issue is being addressed through collaborations of Developmental Disabilities Councils and University Centers for Excellence in Developmental Disabilities (UCEDD). Universities are creating certificate programs for direct support workers. Students earn college credit for this training, thus encouraging them to continue to work on a college degree and increase their career advancement in the field. [33] Pittsburgh and Allegheny County have a rich resource in their universities. Pennsylvania is using a similar model for early intervention providers for young children with disabilities--the Keystone STARS program, an initiative of the Office of Child Development and Early Learning (OCDEL). Its goal is to improve, support, and recognize the continuous quality improvement efforts of early learning programs in Pennsylvania.[34] Individual workers and programs are able to progress through increasing levels of professional certification through training and demonstration of professional competency. [35]

The ACT advisory committee recommends that United Way support initiatives to replicate the Keystone STARS model for direct support workers by partnering with a local university for the

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[29] http://livingwage.mit.edu/counties/42003

[30] Joint Position Statement issued by the American Association of Intellectual and Developmental Disabilities (formerly AAMR) and the Arc of the United States, 2008

[31] Hewitt, A.S., &Larson, S.A. (2007). "The direct service workforce in community supports to individuals with developmental disabilities: Issues, implications and promising practices." Mental Retardation and Developmental Disabilities Research Reviews, 13, 178,187).

[32] See Appendix 1C(x) for full statistics from survey and comments.

[33] Oklahoma Developmental Disabilities Council, *www.okddc.**ok**.gov/*

[34] "STARS" = Standards, Training, Assistance, Resources and Support.

[35] See http://www.pakeys.org/pages/get.aspx?page=Programs_STARS

creation of a certificate or degreed program for direct care workers. Salary increases for workers could be tied to the number of "certified" skills they achieve. Degree and/or certificate granting programs would enhance the professional status of direct support workers and encourage them to think of their work as a career. As dedication to the profession and quality of care increase, Direct Support Workers and the individuals they serve can develop long-term mutually beneficial relationships.

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5. *Recommendation: Create and support initiatives which address the complications of transition from the pediatric to the adult system of medical care.*

Children with complex needs have been well served by the world class physicians at the Children's Hospital of Pittsburgh. Special, interdisciplinary clinics address complicated life-long conditions. The supportive partnership between medical practitioners, parents and children changes when a child turns 18 and the rules regarding who makes decisions change. Eighteen-year olds are presumed legally capable of making health decisions. In place of the coordinated care found in children's hospital, medical care becomes fragmented, disseminated throughout the community to specialists who may be unfamiliar with complex developmental and mental health disabilities. Knowledgeable medical expertise becomes difficult to find.

Coordination between child and adult systems is essential to ensure long term health and self-determination. Dr. Jonathan Pletcher, a Children's Hospital of Pittsburgh specialist in adolescent medicine, reports that Children's Hospital of Pittsburgh has over 1,000,000 outpatient visits and 13,000 inpatient admissions each year. Approximately 5% of visits/admissions are for youth over 18. These statistics, he says, translate to about 50,000 opportunities to discuss transition to adult health care with patients 18 and older.

Practitioners in the adult health care system rarely have a deep knowledge base about individuals with developmental disabilities. The origin and the etiology of developmental disabilities, long-term outcomes, and psychological and behavioral support strategies are not required core curricula:

> *"There is broad agreement at the national level of the urgent need for improved training of health professionals regarding the care of individuals with intellectual or developmental disabilities. In spite of the ready availability of on-line curricula and training tools, there is little evidence that medical students are exposed or are granted opportunities to learn about or practice caring for this group of individuals who might very likely make up the majority of their patient base".*
>
> *--Dr. Jonathan Pletcher, CHP*

The result is that adult health care providers are ill equipped to support increasing numbers of adults with complex needs. The Administration on Intellectual and

Developmental Disabilities makes recommendations for better training for medical professionals, including increasing awareness of IDD within the entire medical community and ensuring informed consent in all health care decisions.[36]

In the secondary educational system, opportunities to discuss transition to adult health care arise within the IEP process. Students with complex needs should be directly taught to maximize their abilities to participate in dialogues and choices about their health and wellness.

Almost all (95.8%) of the respondents to the ACT "individuals and family" survey said they were either "very interested" or "somewhat interested" in efforts to assist with medical transition. Nearly 100 respondents commented about the difficulty of medical transitions. Most of these comments referred to difficulties with insurance coverage, physicians' understanding of disabilit(ies), and physicians' assumptions that patients with complex needs are not capable of participation in their own healthcare decisions. [37]

The ACT study also found that coordination of care-- and payment for this service-- is a concern of individuals and families. The "medical home" model offers the potential to address this issue by replicating the role of the pediatrician with the adult primary care physician as the hub. The increased use of the "medical home" model can improve access to health care, increase patient satisfaction, and enhance health outcomes.[38] Care coordination, an essential component of the medical home model, requires additional resources such as health information technology, and appropriately trained staff. Additionally, payment models that compensate for coordination activities encourage the use of this model.

United Way could support the collaboration between systems to create and disseminate information to all adult medical service providers by:

- Collaborating with school-age service providers, educators, support coordinators and health care providers to develop a public awareness campaign about the unique issues facing transition-aged individuals with complex needs -developing and disseminating brochures that highlight these issues to health care providers. This project could complement the project recommendations for issues 1 and 2 above.

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[36] See http://www.acf.hhs.gov/programs/aidd/resource/pcpid-quarterly-meeting-september-2627-2011?page=9

[37] See APPENDIX 1C(vi) for statistics and comments regarding medical transition

[38] The medical home, also known as the patient-centered medical home (PCMH), is a team based health care delivery model that provides comprehensive and continuous medical care to patients with the goal of obtaining maximized health outcomes (American College of Physicians) (American Academy of Family Physicians). Joint principles that define a PCMH have been established through the cohesive efforts of the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), American College of Physicians (ACP), and American Osteopathic Association (AOA).
See http://en.wikipedia.org/wiki/Medical_home

- Supporting measures that would allow primary care physicians to bill for indirect medical support services like coordination, research and referrals offered to and extra time spent with patients with complex needs.
- Supporting measures that will change the curriculum in regional medical schools to mandate training in developmental disabilities, etiology, psychology and long term care.

6. Increase and improve residential living options for individuals with complex transition needs.

Today, although more individuals with complex needs live in "community" rather than institutional settings, many do not enjoy the choice of where and/or how they will live and many continue to have restricted lives.

Many continue to reside with their families because other residential options are not satisfactory. Group homes may not be appealing because the model often forces individuals to live with people they did not choose. Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICF/IDD), nursing homes or institutions are their only other options for health and safety.

Living in a welcoming community near family, friends and social circles enhances natural supports, builds social capital, and creates long-term living support that are not dependent on public dollars or systems.

For individuals with complex needs, developing a welcoming community involves creating:

- Physically accessible, walkable communities with accessible public transportation
- Co-housing models where individuals of different and complimentary ability level my share a home or community. This community can be created as an inclusive model from its inception.
- Meaningful, accessible recreational activities within the larger community or within the community living arrangement itself

The Act study finds interest among family members regarding residential options for young adults with complex needs. The ACT study shows that the government-funded residential support system is economically unsustainable and does not meet the needs of individuals with complex needs. [39]

Promising local efforts address the need for more consumer-driven options. For example, "The Integrity Project" sponsored by the Tender Loving Home Health Care Agency envisions a fully-integrated community environment that provides consumers with the safety and security they

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[39] See APPENDIX IC(viii) statistics and comments

need and the dream opportunities they want. The homes in the project are enhanced by technology such as iPads to facilitate communication with family and friends, as well as to enable staff to monitor medications and behaviors. The project promises a replicable model for community living for individuals with the most significant disabilities.

The United Way 21andAble project's "Residential Working Group" has a clear vision for appropriate residential supports. Stakeholders maintain that residential supports must be sustainable, accessible, safe, affordable, integrated in the community, creative, innovative and enhanced by technology. To be effective, residential support must also ensure privacy. Additionally, the Residential Working Group holds that "systems" must offer choices, ensure that support staff are well trained, competent and paid sustainable wages, promote home ownership, educate and promote independence, and seek out innovative public-private partnerships.

Individuals with complex needs and their families have access to circles of support, life sharing, new communication technology, Microboards, and waiver funding. Some organizations are beginning to explore new housing models and smart homes and to create more support for families in their own homes.

However, the burdensome regulatory climate, recent increase in admissions to state centers, high staff turnover rates, uncertainty of provider rates, and the looming impact of block grants continue to cause angst in a system that is already underfunded and has long waiting lists for services.

The ACT study recommends supporting the efforts of 21 and Able' "Residential Working Group" to support and promote sustainable and innovative housing projects, home ownership, public-private partnerships, community awareness, realistic preparation for adulthood during the school years, and university collaborations.

CONCLUSION

United Way envisions a world where all individuals and families achieve their human potential through education, income stability and healthy lives.[40]

Promoting this vision for adults with complex transition needs requires high quality human services that focus on person-centered planning, self-determination and community inclusion. The vision requires effective leadership from service providers, people with disabilities, and their families and friends.

In keeping with this vision, the ACT study recommends that United Way support local and state-wide policy initiatives that improve service delivery of adult medical support, expand residential housing options, and encourage well-educated, adequately-paid direct support workforce.

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[40] http://www.unitedway.org/

The ACT study also recommends that United Way pilot initiatives that encourage the use of available life-planning tools, establish opportunities for individuals to continue building functional communication skills, and increase the capacity of day options in the community. By supporting such policies and initiatives, United Way will be assisting people with severe disabilities and complex needs in expressing their personal preferences, communicating effectively, enhancing their health and leisure options, creating “interdependence” and living meaningful lives.

As United Way commits to improving outcomes for transition-age youth with the most significant and complex needs, it will create a strong foundation upon which individuals of all ability levels can build healthy lives of their own choosing.