

Running head: IL

Independent Living

A white paper written by youth leaders from the Youth Leadership Development Institute
2011

To request the right to duplicate this white paper please call the PEAL Center at 412-281-4404 or
visit their website at pealcenter.org

Table of Contents

Youth Leadership Development Institute.....	2
Introduction to the Youth Leadership Development Institute (YLDI)	2
Purpose of the YLDI	2
Youth Leadership Development Institute White Papers	2
Introduction to the White Papers	2
Development of the White Papers.....	3
Introduction and History of Independent Living.....	4
Funding	5
Lack of Available Funding.....	5
Transition and Changes in Requirements	6
Waiting lists.....	7
The Catch-22 of employment.....	7
Difficulty finding funding sources and service providers.....	9
Personal Care Attendants	10
Lack of adequate personal care attendant reimbursement	10
Assistive Technology.....	11
Housing.....	12
Lack of Access.....	12
Lack of budgeting assistance.....	12
Emergencies.....	14

Youth Leadership Development Institute

Introduction to the Youth Leadership Development Institute (YLDI)

The Youth Leadership Development Institute was established through support from the Maternal and Child Health Bureau's State Implementation Grant. This Institute worked to promote the development of advocacy and leadership skills in youth with disabilities. The developers of the curriculum believe in the importance of creating youth-led and youth-focused programs in order to develop a network of peer mentors. Youth who attended these events were between the ages of 16-28, had a disclosed disability, and were identified as emerging leaders.

Purpose of the YLDI

The goal of the YLDI is to provide a safe, accepting environment to cultivate the growth of self-acceptance, confidence, and self-advocacy skills. Youth leaving the YLDI program should feel more accepting of themselves with a disability; more confident in their abilities and choices; and more connected to fellow youth at YLDI and to the disability community as a whole.

Youth Leadership Development Institute White Papers

Introduction to the White Papers

In recognition of the limited amount of time they had together, the members of the YLDI decided that they wanted to leave a legacy of the work they had done as a group. There are a number of barriers that youth with disabilities commonly face, that, when unaddressed, can result in devastating consequences. In recognition of these issues, the group began developing a set of twelve white papers identifying the discrimination and barriers that youth endure.

Development of the White Papers

In November of 2009, the first YLDI was held in Cranberry, Pennsylvania. Approximately twenty youth with disabilities attended this event, and from that group eight youth were selected to take on leadership positions for future YLDI events. Over the next two years, three additional YLDI trainings were held, and from those three, twelve additional leaders were chosen to assist in creating training materials, leading sessions, speaking to officials about youth issues, and creating white papers. In the last year of the program, these twenty leaders attended advanced leadership institutes where they assisted in developing the twelve white papers.

During this two-year endeavor, the twenty leaders (ages 16-29) met on four different occasions to identify top issues faced by youth, define sources of the problems, and create recommendations. These four weekend meetings produced the foundation of each of the twelve white papers. Topics include:

- Employment
- Education
- Self-Advocacy
- Healthcare
- Independent Living
- Youth Leadership Development
- Social Relationships
- Disability Stigma
- Transition
- Transportation
- Top Issues: Summary of Concerns

Several members of the group volunteered to further develop these foundational documents into policy papers. Each paper was then edited by the other leaders. The resulting white papers are to be used to identify the barriers faced by youth and to recognize the importance of the youth voice in developing solutions.

Please email Josie Badger at josiebadger@hotmail.com with any questions, comments, or to request a presentation.

Introduction and History of Independent Living

For youth with disabilities, there are many facets of establishing independent living. In general, independent living implies one's ability to lead a self-determined, empowered life, emphasizing maximum independence. Requiring supports does not inhibit one's ability to successfully achieve independent living. However, the lack of support and a lack of funding for supports can prohibit a person from being able to lead a self-determined life with the capacity to achieve his or her maximum potential.

In the United States, the independent living movement began during the civil rights movement. Leaders of the disability rights and independent living movement worked alongside the advocacy efforts of other minority populations to ensure that the rights of people with disabilities were not overlooked. Ed Roberts of Berkeley California is revered as the "father of the independent living movement." After being denied services from Vocational Rehabilitation, he filed a lawsuit in order to be admitted into the University of Berkeley. After graduation, Roberts was appointed as the director of Vocational Rehabilitation and eventually established the Center for Independent Living. These centers are grassroots, advocacy-driven organizations that work to improve the lives of people with disabilities through providing services to support the dignity and empowerment of people with disabilities. This was the beginning of the Independent Living Movement.

In the following report, youth leaders with disabilities have identified barriers faced in independent living and have made recommendations for resolutions.

Funding

For individuals with disabilities, the ability to live independently is often reliant on the provision of necessary equipment, services, and supports. These assistive measures require additional financial resources, often not readily available to the person or family concerned. Although cheaper than institutionalization, the necessary services for home care and independent living are often too expensive for most families. The provision of funding can allow people with disabilities to become productive citizens and provide the support necessary to keep families together.

Currently, governmental agencies and insurance providers maintain a medical model of disability, believing that disability is an illness which needs to be cured. Additionally, it is often assumed that the best care for people with disabilities can be provided by a medical and institutional environment. This outdated view does not recognize the dignity of humanity with its inherent right to self-determination free from bondage. Institutionalization not only limits one's freedom, but also places a large, unnecessary financial burden on society without recognition of an individual's ability to be a productive, valuable citizen. Conversely, channeling funds to support independence living can decrease the costs of medical services provided to citizens while recognizing their human dignity.

Lack of Available Funding

PROBLEM

Unfortunately, governmental budget cuts directly influence the availability of independent living services for people with disabilities. These services are often classified as auxiliary supports which are not required for survival. However, the effects of these cuts on people with disabilities and the burden of inflated costs they place on other systems often go on unrecognized. Individuals with disabilities often rely on independent living services such as Social Security income, funding for personal care attendants, travel expenses, assistive technology, and reimbursement for medical expenses to survive. When their needs are not met, other needs and additional medical expenses may occur. Organizations or departments often separate supports, services and funding based on their target population. Factors can include: age, class, economic status, diagnosis or disability, location, gender, ethnicity, and other varying diversity factors. These divisions can make it difficult for individuals to locate and receive approval for the provision of services and funding.

Often there is a lack of equal distribution of services to vulnerable populations, ultimately creating multiple vulnerable populations.

RESOLUTION

Continuity of care- State and federal departments need to collaborate in creating a continuum of care, individualized for people with disabilities who rely on support services. Often, as one department or service provider cuts supports, others are forced to absorb the expenses, creating a cyclical affect which is not ultimately beneficial to the individual or the government. There must be an effort to find promising practices which promote each citizen's ability to maintain independence and ability to contribute to society. For example, providing funding for assistive technology and personal care attendants can prevent the need for an individual to live in a nursing home, ultimately lowering the cost of providing care for the individual and allowing him or her to pursue employment options. The current economic crisis requires a holistic approach to macro-level financial stewardship. Therefore, cutting the budgets of certain departments or systems can no longer serve as the primary method for debt control.

Transition and Changes in Requirements

PROBLEM

As young people age and begin transitioning into adulthood, they often experience changes in eligibility requirements for their services and funding. Many services are provided on an entitlement basis for children and adolescents, but are only available to adults through eligibility for application. The requirements for eligibility for adult services are often stricter, with a limited number of consumers served. This often creates a gap or loss of services for young adults with disabilities, further challenging the transition process.

RESOLUTION

Standardization of disability- Service providers often have their own definitions of disability, eligibility for services, and the age of transition. This can cause confusion for both the consumer and provider, decreasing

efficiency and increasing the difficulty of transition. These definitions of eligibility must be standardized throughout all systems and providers.

There must be an established transitional period for all youth with disabilities who receive services in which youth-based providers work to refer clients to adult services. This would require increased transitional training for youth and families, in addition to further collaboration between youth and adult services.

Waiting lists

PROBLEM

In the state of Pennsylvania, after a youth has been recognized as an adult, he or she is provided services through state waivers. For individuals to receive services through these waivers, he or she must meet eligibility requirements to be placed on waiting lists. Services become available after other individuals no longer receive the waiver (often due to the consumer's death), and placement on these waiting lists is determined on a first-come first-served basis. Unfortunately, it may take several years for an individual to receive waiver supports, regardless of the urgency of the situation or level of support required.

RESOLUTION

Community Choice Act- While an individual remains on a waiting list, he or she continues to require services to survive or maintain a basic quality of life. Often when an individual does not receive a waiver, he or she is forced to become further dependant on the system, resulting in a decreased quality of life and inability to be contributing citizens. The remedial services available to those without waivers are often inefficient and expensive. . Since the passing of the Community Choice Act, people eligible for care in a nursing home are also able to receive attendant care in their own homes.

The Catch-22 of employment

PROBLEM

Although the purpose of independent living services is to support the self-determination and empowerment of individuals with disabilities, these

services are often eliminated when the individual becomes employed or reaches a predetermined income cap. Individuals who lose these supports are often unable to maintain independent living or competitive employment, forcing further dependence on the system. Even for the individual who makes a survivable and competitive wage (over minimum wage), it is nearly impossible to pay for necessary services. This often forces individuals to choose between independently living on a meager income with supports, working without necessary services, or remaining unemployed.

RESOLUTION 1

To implement an automated system for the provision of governmental financial assistance (revising SSI and SSDI pay structures) to include a sliding scale based on monthly income.- A predetermined amount of governmentally provided financial aid would be based on an individual's needs assessment, including living, medical, and disability-support expenses. This system would monitor an individual's monthly net income and adjust the predetermined amount of financial aid accordingly. Therefore, if a needs assessment determines that an individual can receive \$1,000 of financial assistance, then he or she would also be able to earn up to that amount without losing benefits or incurring a deduction in financial aid. However, once the individual exceeds the \$1,000 income cap, the amount of financial aid will decrease dollar-for-dollar accordingly. Although the amount of financial aid will decrease with excess income, the amount of services, insurance, or medical assistance should not be affected.

RESOLUTION 2

Needs based support- Individuals who receive disability services or independent living supports often face the threat of losing critical services when pursuing employment or reaching an income cap. This can force a person to remain unemployed and dependent on governmental supports. Having the ability to obtain and maintain competitive employment does not eliminate a person's need for services. Therefore, support for activities of daily living should not be based on income or employment status. Services should be focused on supporting the needs of an individual to achieve and maintain their unique and highest potential.

Difficulty finding funding sources and service providers

PROBLEM

Even when funding is available for technology, services, and supports, it is often difficult to locate these funding sources and service providers. Finding sufficient and necessary services requires a tremendous amount of time, skills, and patience, which are often lacking in the family or with the individual with the disability.

RESOLUTION

Referral responsibility- Disability and support services should have the obligation of acting as referral services for consumers. This could help support consumers and minimize the replication of services, eliminating excess costs.

Personal Care Attendants

Personal care attendants provide a priceless service in the empowerment and the independence of people with disabilities. They are able to maintain independent living while supporting a sense of dignity and respect for the population. The services that they provide may include food preparation, feeding and support in hygiene activities and other activities of daily living.

Lack of adequate personal care attendant reimbursement

PROBLEM

Currently, there is a lack of available funding to pay for the adequate reimbursement of qualified personal care attendants. This lack of financial support limits the quality of individuals who apply for care attendant positions and increases the turnover rate. Additionally, with inadequate reimbursement rates and lack of benefits, many individuals are unwilling or unable to accept these demanding positions. It is also difficult to locate potential employees who have the skill set necessary to work in this field. Even when a qualifying and accountable personal care attendant is hired, there is often a lack of funding for the necessary number of hours that the consumer may need in order to achieve an independent, high-quality life.

RESOLUTION

Collaboration- Supporting collaboration between service providers to deliver comprehensive supports with adequate reimbursement rates for care providers.

Assistive Technology

PROBLEM

Assistive technology can independently support the needs of people with disabilities without the constant care or supervision of other individuals. Unfortunately, funding for these devices is often cut first in attempts to lower the budget. The elimination of technology, however, often increases a person's needs and can limit his or her productivity, creating a counterintuitive situation.

RESOLUTION:

Lending libraries- Although as a budget item this seems like an easy place to save money, the elimination of these services eliminates a consumer's ability to try technology or assistive devices prior to having service providers for him or her. This money can go to waste if the device does not fit the needs of the consumer. Funding for lending libraries should be reinstated to ultimately decrease expenditures on assistive devices.

Housing

Accessible, affordable, safe housing for people with disabilities is often difficult to locate and secure. Many building standards do not require newly built, personally owned homes to meet accessibility standards. Therefore most homes on the market are unavailable to people with disabilities. Government housing developments have accessibility requirements, but many are located in unsafe areas, creating greater vulnerability for people with disabilities.

Lack of Access

PROBLEM

There is a large disparity of accessible housing. Even when an apartment is advertised as accessible, access is often met at its minimum standards. Individuals must often settle for housing that is "almost accessible" or has substandard accommodations.

RESOLUTION

Tax incentives and loans- Through offering tax incentives and low interest loans for making accessible housing, the government can support grassroots housing agencies and contractors in creating accessible homes.

Lack of budgeting assistance

PROBLEM

Formal education rarely provides information on budgeting, financial management, and other practical responsibilities. Many individuals are unable to manage their finances, and this ultimately affects their credit and ability to obtain or maintain housing.

RESOLUTION 1

Teaching financial management- School systems need to make a concerted effort in educating students on financial management. Teachers need to collaborate with transition coordinators to ensure that this is part of each student's education and transition plan.

RESOLUTION 2

Budgeting assistance- Certain financial institutions offer bill and budget assistance programs in which an individual can sign up and allow the bank to deduct a certain amount of money each month to pay for bills. The bank will provide an allotted amount of personal spending money to the individual each week. This will ensure that all bills are paid in a complete and timely manner while preventing the individual from overdrawing his or her account. Although programs such as these limit the amount of activity an individual has in his or her account, it can increase independence and knowledge about budgeting.

Emergencies

PROBLEM

To be able to live safely and confidently in one's community, it is critical to know that first responders and emergency care providers are educated and prepared to manage the needs of people with disabilities. This implies that first responders are unable to identify a person with a disability, understand his or her needs, and care for those needs.

RESOLUTION:

Training sessions should be made available to all individuals to promote the use of In Case of Emergency information cards, as well as cell phones. This information will help first responders recognize and determine the right course of treatment in emergency situations.

All first responders and emergency care providers should be certified in disability awareness and safety. It is critical not only to be able to identify a disability or a potentially dangerous situation and recognize how to work with a person with a disability, but also to respect his or her dignity.